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THE SOCIAL CONSEQUENCES OF HYPOTHYROIDISM: MANAGING THE TRAJECTORY

BY

PATRICIA JANE MILLIKEN

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ABSTRACT

This study examines the experience of women suffering from hypothyroidism. By applying Anselm Strauss's substantive theory of a chronic illness trajectory to hypothyroidism, the course of hypothyroidism is traced. Because the symptoms of this illness tend to be vague, subjectively experienced, insidious in onset, and cyclic in occurrence, many sufferers are required to engage in a process of "seeking validation" for their illness in order to receive appropriate treatment. A grounded theory of "seeking validation" is described.

Participants were a convenience, snowball sample of twelve adult women. Transcripts from semi-structured interviews were analyzed by the constant comparative method of grounded theory.

Information from this research will be helpful to other hypothyroid sufferers, and will assist their caregivers and families in achieving an empathetic understanding of the illness from the sufferer's perspective.

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CHAPTER ONE

INTRODUCTION

The thyroid, a butterfly-shaped gland located in front of and around the larynx in the neck, is responsible for growth regulation and the thermostatic control of the body's metabolism. Malfunction of the thyroid gland occurs in one of two ways: over-production or under-production of thyroid hormone. The former, called hyperthyroidism, produces an excess of thyroid hormone and an increase in the body's metabolic rate. The latter, hypothyroidism, causes a deficiency in the level of thyroid hormone and a decrease in the body's metabolism. The second condition is the focus of this thesis. The study does not address the various biological processes associated with hypothyroidism but rather examines the psycho-social effects of the disease on the afflicted individual.

A. The Problem

Hypothyroidism is a chronic disease. Mayo outlined the criteria for a chronic disease as follows:

> All impairments or deviations from normal which have one or more of the following characteristics:
> -are permanent,
> -leave residual disability,
> -are caused by non-reversible pathological alteration,
> -require special training of the patient for rehabilitation,
> -may be expected to require a long period of supervision, observation, or care (1956, cited in Strauss, 1975:1).

Hypothyroidism fulfills the above criteria. In the vast majority of cases[1], it is a permanent condition involving non-reversible changes in the thyroid gland and requiring life-long monitoring of thyroid function, both clinically and through periodic laboratory testing. The medical literature largely ignores the question of whether hypothyroid sufferers are left with any residual disabilities and fails to describe any physical, psychological, or social adjustments they must make in order to adapt to their disease and to attain optimal recovery.

B. Theoretical Perspective

In 1975, Anselm Strauss developed a theory to describe and explain how people live with chronic illness. He proposed the concept of a disease trajectory that focuses on the course of a chronic disease as it is defined by its participants. A trajectory has both a temporal dimension (i.e., it is a process occurring over time) and a shape. As such, it may be represented by a graph, tracing the phases of a disease process as the sufferer becomes worse (a

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1 In rare cases, subacute thyroiditis secondary to a viral infection will show the signs and symptoms of hypothyroidism, although the usual clinical picture is of euthyroidism or hyperthyroidism. A painful and swollen thyroid is accompanied by fever and malaise. The disease tends to remit spontaneously but it often recurs in a two to three week cycle, eventually subsiding completely in one to twelve months (DeGroot, 1975).

The occasional woman develops hypothyroidism following pregnancy, probably due to a surge in the production of thyroid antibodies. This may remit spontaneously after a few months or it may result in permanent hypothyroidism (DeGroot et al., 1984:526).

downward trajectory), improves (an upward or recovering trajectory) or reaches a plateau (horizontal movement of the trajectory). Each phase of the trajectory requires that she[2] develop strategies in her personal lifestyle and social relationships in response to the new problems and changes in physical functioning presented in that phase. In short, the sufferer of a chronic illness needs to learn to "manage her trajectory".

The central goal of this research project is to define the disease trajectory for hypothyroidism. In doing so the thesis describes how people tend to cope with hypothyroidism. As Strauss said, "Each type of chronic illness...or subtype...may have some range of variation in trajectory, but each certainly tends to have a general pattern" (Strauss, 1975:47).

C. Research Hypothesis

Strauss's illness trajectory traces an illness from its diagnosis. However, it is important to recognize that symptoms appear prior to the diagnosis; thus, the trajectory is already in motion at the time of the diagnosis. From examining the literature one would hypothesize that the general pattern of the trajectory for hypothyroidism would move downward from the first appearance of symptoms and the realization that "something is wrong" to the time of diagnosis, and then upward following the initiation of

---

2 Because the majority of thyroid disease sufferers are female and because the subjects in this study are all women, the feminine pronoun will be used throughout this thesis.

thyroid replacement to a level of equilibrium at or below the person's pre-symptom state. The study described below examines this hypothesis by comparing the reported illness experiences of women sufferers of hypothyroidism.

CHAPTER TWO

LITERATURE REVIEW

In order to begin defining the general pattern of hypothyroidism, this review of the pertinent literature focuses on three content segments: hypothyroidism as a disease, hypothyroidism as an illness, and some related theoretical concepts. Medical sociologists discriminate between disease and illness (Eisenberg, 1977a). A disease is a medical phenomenon, a pathophysiological condition distinguished by an identifiable group of physical signs and symptoms. In contrast, an illness is defined in social and psychological terms through the subjective perception, behavior and individual experience of the sufferer. While the disease and illness are related and usually occur together, they may also occur separately. For example, a particular individual may feel ill in the absence of any identifiable disease, while another person may have biological changes characteristic of a disease and not feel ill. This literature review concludes by examining several studies of chronic diseases in order to offer a framework of theoretical concepts for studying the experience of a woman living with hypothyroidism. Studies that employ the grounded theory method comprise this aspect of the review.

A. The Disease

Goiter, an historically recognized form of hypothyroidism, has historically been endemic in land-locked mountainous areas of the world where glacial movement has depleted the soil and drinking water of iodine. Iodine is necessary for the normal functioning of the thyroid gland and its synthesis of thyroid hormones. Goiter, the enlargement of the thyroid gland in the neck in an effort to increase thyroid hormone production, is the body's compensatory response to a low level of thyroid hormones circulating in the blood. Sometimes the increased thyroid tissue succeeds in keeping the person in a euthyroid state and she remains well. In many cases the iodine deficiency is severe enough to cause hypothyroidism. Adding iodine to the diet primarily through the widespread use of iodized salt has largely, but not completely, eradicated simple goiter in the developed areas of the world (DeGroot, 1975; Fowler, 1960).

While endemic goiter from a lack of dietary iodine has been virtually eliminated in developed countries, hypothyroidism (from causes other than dietary iodine deficiency) still occurs. Underactivity of the thyroid gland in the adult may result from treating hyperthyroidism with surgical removal or radioactive destruction. An autoimmune process in which the body produces antibodies against the thyroid can also destroy the gland. As well, certain drugs will interfere with hormone production.

Finally, a small number of people produce sufficient quantities of thyroid hormones but their cells are unable to efficiently utilize the hormone in metabolism.

1. Incidence and Prevalence

Despite a reduction in prevalence, hypothyroidism remains a common medical problem, but assessing the extent of the problem in the population is not an easy task. Because hypothyroidism results from several different pathological conditions and because experts suggest that a large proportion of hypothyroidism remains undiagnosed in the general population, estimates of its incidence and prevalence are difficult to interpret. Reported statistics are based on a variety of different forms and severities of thyroid disease and on different kinds of measurement.

In 1978-1979, 1.2% of Canadians reported having a thyroid disorder[1] (Health and Welfare Canada, 1981). Of this group 86% were females and 14% were males. Prevalence of thyroid disease increased with age but was unrelated to family income. In the fifteen to sixty-four year age group, 2.7% of women and 0.3% of men reported thyroid problems. This prevalence increased for those over sixty-five years of age to 4.5% for females and 1.7% for males. That 1.2% of Canadians are afflicted with thyroid problems can be compared with the self-reported prevalence from the same large-scale survey of diabetes, 1.5%, and anaemia, 1.6%,

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1. This includes thyroid diseases of all types and does not distinguish between hypothyroid and hyperthyroid conditions, infections, or malignancies.

both of which are much more widely recognized conditions. It is important to realize that these figures represent self-reported health problems and indicate both acute and chronic conditions at the time of the interview. Because, as shall be explained later, thyroid conditions are often unrecognized or masked by attendant psychiatric symptoms, the above figure is probably a conservative estimate.

This underestimation is also suggested by studies from other countries reporting figures for hypothyroid conditions alone. A large epidemiological study in England found that while overt hypothyroidism (i.e. hypothyroidism with obvious symptoms) affected 1.4% of the adult female population and that the condition in females outnumbered that in males by fourteen to one (Tunbridge et al., 1977), nevertheless three percent of the sample (5.1% of females and 1.1% of males) were found to have thyroid antibodies and elevated TSH levels[2]. Thyroid antibodies are a sign of autoimmune thyroiditis which sometimes but not always shows clinical signs and symptoms of hypothyroidism and which research indicates is the most frequent thyroid disorder today (Fisher et al., 1975, cited in Hall et al., 1982). Autoimmune disease of the thyroid may be increasing in incidence (Fowler, 1960; Furszyfer et al., 1970; Macksood et al., 1961), although Masi (1965) suggests that this is probably an apparent gain, reflecting better detection and

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2 TSH, thyroid stimulating hormone, is produced by the anterior pituitary in response to low circulating levels of thyroid hormone. TSH stimulates the thyroid gland to produce thyroid hormones.

awareness of the condition rather than a true increase. Masi's thirteen year review of autopsies at Johns Hopkins Hospital in Baltimore pegged the prevalence of autoimmune thyroid disease in white females at two percent. Research suggests that autoimmune thyroiditis is approximately four times more common in females than males (Beall and Soloman, 1973; Fowler, 1960, Masi, 1965). The ratio, however, may be as high as eight to ten women for each male (Hall et al., 1982). It is probably three to four times more common in white people than black (Beall and Soloman, 1973; Masi 1965) and the incidence tends to increase with age (Sawin et al., 1979) and following pregnancy (Beall and Soloman, 1973; Dahlberg and Jansen, 1983). These studies suggest that hypothyroidism is a common condition, probably more common than is widely recognized.

2. Physiology

Any interruption or abnormality in the normal chain of reactions through the hypothalamus, pituitary gland and thyroid can disrupt the control of thyroid hormone secretion. In very simple terms this control is normally mediated through the following interactions:

1. Reacting to input from the central nervous system about the level of circulating thyroid hormones in the blood, the hypothalamus, which coordinates the functions of the autonomic nervous system, secretes TRH (thyrotropin-releasing hormone).

2. TRH influences the release from the pituitary gland into circulation of TSH (thyroid stimulating hormone).

3. TSH stimulates the thyroid gland to produce thyroid hormones, T4 (thyroxin) and T3 (triiodothyronine) and then release them into peripheral circulation, where they are bound to plasma proteins.

4. The level of circulating T4 and T3 then feeds back on the pituitary to regulate the release of TSH. In addition, information about circulating levels of TSH as well as T4 and T3 is transmitted in a feed-back loop to the hypothalamus to modulate its secretion of TRH. (Gold and Pearsall, 1983) [see fig. 1]

The basic biochemical tests of thyroid function rely on measurements of the above hormones. In hypothyroidism, the typical pattern is a low level of T4 accompanied by markedly

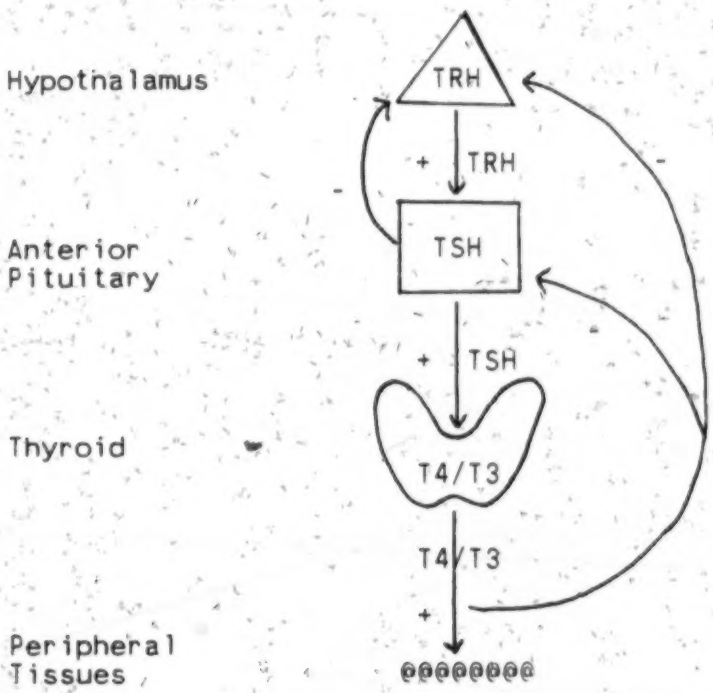

Fig. 1 Control of Thyroid Hormone Secretion.

*source: Fig. 2-5. Evered, 1976:18
-adapted for this thesis

elevated levels of TSH. In overt thyroid failure the T3 level also will be low. Many more sophisticated laboratory tests may be used but the TSH level is generally the best indicator of hypothyroidism (Evered et al., 1973:657).

3. Common Causes of Hypothyroidism

Spontaneous thyroid failure is most commonly caused by an autoimmune process, an inflammation of the thyroid gland (thyroiditis), or dietary iodine deficiency. Other less common causes are developmental abnormalities of the thyroid and abnormalities in either iodine metabolism or hormone synthesis. Hypothyroidism also may be iatrogenic in origin, developing after surgery or irradiation originally undertaken to treat thyroid tumors or hyperthyroidism (Evered, 1976; Gold and Pearsall, 1983). Reduction in the production of thyroid hormones also may occur as a side effect of psychiatric drug therapy, especially lithium (Loosen and Tipermas, 1983) or drug treatment for hyperthyroidism, commonly carbamazepine or propanolol (Wilson, 1985).

Special mention should be made of autoimmune thyroiditis, also called Hashimoto's thyroiditis. Roitt et al., who first demonstrated auto-antibodies to thyroglobulin, an iodine-containing protein produced by and stored within the thyroid gland, suggest that the "destruction of the thyroid in Hashimoto's disease results from progressive interaction of thyroglobulin in the gland

with the auto-antibody present in the patient's circulation" (1956:820).

This is probably the primary cause of hypothyroidism, although the exact pathogenic mechanisms that cause the body to produce antithyroglobulin antibodies and antimicrosomal antibodies have not yet been completely defined. Evered et al. (1973) identified thyroid antibodies in over 85% of hypothyroid patients. Masi (1965) proposes that chronic thyroiditis and Hashimoto's are likely the same disease. There is also some indication that Graves' Disease, the major hyperthyroid syndrome, and Hashimoto's disease represent opposite ends of the spectrum of a single autoimmune disorder (Jaffiol et al., 1983; Wilson and Jefferson, 1985) as many patients who recover from Graves' disease will later develop Hashimoto's. Approximately seventy percent of respondents to a survey of the Thyroid Foundation of Canada reported suffering from either Hashimoto's thyroiditis or Graves' disease (Hudacin, 1985).

Hypothyroidism has been linked to a number of other diseases. Patients with auto-antibodies specific to one organ will often develop other autoimmune disease. Leznoff et al. (1983) discuss autoimmune polyendocrine disease. Autoimmune thyroiditis has been linked to pernicious anaemia, idiopathic adrenal atrophy, Sjogren's syndrome, systemic lupus erythematosis, myasthenia gravis, diabetes mellitus (Hall et al., 1982), rheumatoid arthritis (Beall and Soloman, 1973; Hall et al., 1982), and chronic urticaria

and angioedema (Leznoff, 1983). Hashimoto's disease has also been linked to chromosomal disorders such as Turner's syndrome and Down's syndrome (Beall and Soloman, 1973), as well as both obesity (Rimm et al., 1975) and anorexia nervosa (Rippere, 1983; Walsh, 1980). Walsh, however, suggests that the changes in thyroid hormones in anorexia are non-specific attempts by the body to adapt to a state of caloric deprivation.

The bulk of recent research into the causation of hypothyroidism has concentrated in the fields of neuroendocrinology and neurobiochemistry upon the hypothalamic - pituitary - thyroid axis . Secretions from the hypothalamus control visceral activities to maintain water balance, sugar and fat metabolism, body temperature and secretion of the endocrine glands. Both the sympathetic and parasympathetic nervous systems come under its control. The pituitary gland has been called the "master gland" of the body, referring to its regulation of many body processes, including growth, reproduction, metabolism and endocrine function. Because of the multitude of interconnections and feed-back loops within the endocrine and autonomic nervous systems, there is an overlap of signs and symptoms among many disease processes, making exact diagnosis difficult. As a result the ultimate mechanism which causes any of the above related diseases will be difficult to isolate.

Despite the wide variety of pathological conditions causing hypothyroidism, it is the clinical signs and symptoms that cause distress to the patient and provide clues for diagnosis by the physician. The problem with diagnosing hypothyroidism is that the symptoms, especially early ones, are non-specific and the onset of disease is usually gradual. The earliest symptoms are usually lack of energy and tiredness, accompanied often by anorexia (reduced appetite) and constipation. Other early clinical features may be weight gain, hair loss, dry skin and hair, cold intolerance, and excessive and perhaps painful menstruation, i.e. menorrhagia (Evered, 1976). Such symptoms are common among middle-aged women and therefore are often discounted as signifying menopause by them, as well as by their physicians. The most common physical signs and symptoms as listed by Evered (1976:89) are outlined in Table 1.

Often the accompanying psychiatric symptoms will prompt the sufferer of hypothyroidism to see a doctor. Untreated patients will display forgetfulness, carelessness and difficulty concentrating, which can be confused with the symptoms of early Alzheimer's disease. Increasing cognitive impairment is accompanied by progressive depression. In fact, almost all hypothyroid patients report some degree of depression. Haggarty et al. suggest that even marginal hypothyroidism, where thyroid hormone levels are within the normal range, can be associated with depression and that "determination of TSH levels should probably be part of the

TABLE ONE

CLINICAL FEATURES OF OVERT HYPOTHYROIDISM IN THE ADULT

System	Common Clinical Feature
Gastrointestinal	Reduction in appetite
	Constipation
Skin	Dry, cold, puffy, pale
	Hair--dry, coarse, brittle
	Loss of hair
	Nails--thin and brittle
	Yellowish tint (carotinaemia)
	Infiltrative dermopathy (deposits of mucous-like secretions in the skin, especially around the eyes and on the fronts of the lower legs)
	Diminished sweating
Cardiovascular	Bradycardia (slowed heart rate)
	Reduced cardiac output
	Cardiac enlargement
Neurological	Lethargy
	Somnolence
	Headache
	Delayed tendon reflexes
	Median nerve compression (causes "tingling" of fingers)
	Perceptive deafness
	Decreased taste and smell
Muscular	Aching and stiffness
	Weakness
	Joint pain
Reproductive	Menorrhagia (heavy, painful menses) or amenorrhea (no menstruation)
	Reduced fertility
Metabolic	Weight gain
	Lack of energy
	Cold intolerance
Miscellaneous	Hoarseness and deepening of voice
	Thick tongue
	Pathological fatigue (i.e. made worse by sleep)

*source: Table 5-3, Evered, 1976, pg. 89
Table 1, Hall, 1983, pg. 10
-combined and adapted for this thesis

minimal evaluation of most depressed patients, particularly depressed patients with cognitive dysfunction" (1986:786). Occasionally, though, the hypothyroid person may appear hyperactive or manic instead of apathetic and withdrawn (Wilson, 1985). Anxiety and irritability are other common manifestations of hypothyroidism. For many people with hypothyroidism the psychiatric symptoms are very severe, with periods of extreme restlessness, generalized agitation, disorientation, paranoia with persecutory delusions, as well as both visual and auditory hallucinations (Hall et al., 1982). Such symptoms of full blown myxedema[3] are graphically described in a novel by A. J. Cronin (1937). Although uncommon today (Shaw et al., 1985), myxedema still can produce an incurable psychosis and even death (Asher, 1949).

4. Response to Treatment

The medical literature states that patients' physical and psychiatric symptoms usually respond well to thyroid hormone replacement therapy, although recovery can sometimes be slow and frustrating. In many cases there are fluctuations in thyroid functioning during the course of the disease as well as during drug therapy. In rare cases the disease may go into remission spontaneously without treatment (Riddervold, 1983). Therefore, it is important to

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3 Myxedema is a synonym for hypothyroidism, often used in this day and age to refer to severe forms of the disease.

monitor thyroid function regularly and adjust the dosage accordingly during treatment, which is usually life-long.

B. The Illness

The medical literature reveals only very superficial hints about hypothyroidism from the perspective of the patient. One can certainly speculate what it may mean to a patient when doctors report that onset is insidious (Wilson and Jefferson, 1985), diagnosis is uncertain (Beall and Soloman, 1973) or difficult (Asher, 1949; Hall et al., 1982), and that "recovery can be slow and frustrating with the persistence of symptoms such as irritability and slight cognitive impairment" (Fowler, 1960). In a culture such as ours where physical appearance is so important, one would expect that bloated facial features, weight gain, hair loss and changes in voice quality would also be upsetting. Constant fatigue, drowsiness, weakness, anxiety, depression, cognitive impairment, decreased coping ability, strained social relationships, and non-specific aches and pains are liable to test anyone's self-concept. However, most of what we know about these symptoms of hypothyroidism comes from the physician's experience of identifying the disease and prescribing treatment for it. What is the actual experience of the patient? How do her self concept, social relationships and role expectations change as a result of hypothyroidism?

1. A Case Study

Vicky Rippere (1983) has written an autobiographical account of her struggle with hypothyroidism and of her struggle with the medical profession to obtain recognition of her disease and treatment for it. Hypothyroidism was suspected on clinical grounds very early after the onset of her symptoms. However, at the same time, her thyroid function tests were within normal limits and three years elapsed (during which her symptoms worsened) before she was able to begin replacement therapy. A psychologist, with a history of moderate depression, she felt victimized by:

1. her atypical biochemical form of the disease which revealed T4 levels within the low normal range and no rise in TSH. (Her disease picture was further complicated by many food allergies.)
2. her own doctor's (and several specialists') failure to diagnose thyroid disease because of these atypical laboratory results, and
3. psychiatric labelling.

She describes the onset of her illness at age thirty-three as follows:

> I first became aware that I was ill in the summer of 1976, following an extended period of intense occupational stress. At the time I was already suffering from a chronic clinical depression of moderate severity which was only partially controlled by high doses of tricyclic antidepressants...Although it was the hottest summer for years, I never felt warm. I was weak, ached all over, and became breathless after climbing half a dozen stairs. After meals I felt queasy and often had copious floating diarrhoea....A constant low grade head-ache, dizziness on standing, lethargy, and antipathy for physical exertion because

> it so often led to total collapse and prostration, preceded by chill and a feeling of impending doom, and what appeared to be narcoleptic attacks coming on after meals, did little to improve my outlook on life. I sometimes felt that I was going to die and often wished I would because it would save me the trouble of doing the job myself (pg. 114).

Her own physician initially suspected both anaemia (because of unusually heavy menstruation) and hypothyroidism, rejecting both because of normal laboratory investigation. He reverted to a psychiatric diagnosis of transient situational adjustment reaction, relating it to occupational stress. She describes her reaction:

> This "diagnosis" left me devastated, not only at the loss of hope for some relief from my condition but also at his mortifying readiness to resort to functional psychiatric labels with no discussion of alternative interpretations of the findings. I know my problem was not a situational adjustment reaction because since starting the new job my depression had lifted but my physical state was continuing to deteriorate (pg. 115).

After over a year of misery during which physicians ruled out hypoglycemia and Addison's disease, Ms. Rippere self-diagnosed coeliac disease. Without medical consultation she omitted gluten and milk from her diet and many symptoms cleared. She reports:

> By early summer, though I was still chilly and weak, I felt recognizably human again. It was just as well I did, too, because I'd felt so dreadful in January that I'd made a pact with myself to carry on for another six months; after that, if my state hadn't improved, I intended to finish myself off, because I couldn't take this illness and the absence of help any longer (pg. 117).

Nevertheless, her condition worsened in the fall and winter. On her own she consulted a homeopath, but to no avail. Her physician referred her to more specialists. An endocrinologist suspected that she had an underfunctioning

thyroid as a result of dysfunction of the hypothalamus but, after three weeks of testing during which many other diseases were ruled out, her thyroid function tests were within normal limits and no evidence was found of thyroid antibodies. Ms. Rippere gave up, deciding "to abandon further attempts at getting help from this consultant" (pg. 120).

She turned to friends for help. One, a biochemist, after an intense but non-productive laboratory investigation concluded that a therapeutic trial of thyroid hormone would not hurt, and another friend, a physician, was persuaded to prescribe thyroxin. Her response was immediate.

> Within hours of the first dose, I could feel myself getting warmer....After a few weeks on treatment, my periods resumed. I felt warmer. My skin was less dry and rough, voice less croaky, and as the year wore on my mental acuity as well as physical energy and strength increased. People commented on how much more alive I looked....In the first year of treatment, my work output more than doubled (pg. 121).

Eventually her own general practitioner accepted her illness and took over the prescriptions, adjusting the dosage with her clinical state. When, after a year, her symptoms resumed again, he increased the dosage. This willingness to treat her symptoms rather than laboratory results represents a change in his approach, because at the same time as her condition deteriorated, her circulating thyroid hormones increased, rather than decreasing.

2. Effects of Hypothyroid Illness

Beyond an historical account of her illness and a description of her feelings at different stages, Ms. Rippere highlights five effects of the illness that are, perhaps, more social than medical in interest:

a. Labelling. Previous treatment for migraine headache, premenstrual syndrome and depression likely contributed to the labelling by her medical practitioners of her symptoms as psychiatric in origin. Apart from this type of history and the non-specific character of hypothyroid symptoms, Ms. Rippere suggests an additional reason for why hypothyroid patients may be so labelled. "Perhaps it is simply because so many sufferers are middle-aged women, who are commonly known to be at risk of being dismissed as suffering from functional disorder" (pg. 126).

b. Alternate Forms of Help. Unable to obtain satisfactory treatment from her physicians, Ms. Rippere turned to an alternate healer, a homeopath, as well as to friends. Lay people recognized her illness as did several professionally qualified, but not officially consulted, friends. One of Ms. Rippere's own patients, a myxoedematous woman, questioned whether Ms. Rippere had hypothyroidism from the changes in her voice quality alone.

Self-help also played a very important role in this woman's diagnosis and recovery. An educated person, she supplemented her previous knowledge by reading about endocrinology as well as malabsorbtion syndromes. As a

result she adjusted her diet for relief of some of her symptoms and, convinced that her other symptoms were organically caused and thyroid related, she persisted in efforts to obtain treatment that she considered to be appropriate. That her confidence in the medical profession was eroded by her experience is evident in her concluding statement:

> If I should be so unfortunate as to become ill again, I would think twice before subjecting myself to another possible round of unproductive investigations, information deprivation, adverse reactions, psychogenic dismissal, demoralisation, and wasted time. If I were in any position to do so, I would again try to sort myself out rather than handing myself over to the experts (pg. 127-128).

c. Residual Symptoms. Her recovery, even with thyroxin replacement, has not been complete. Physically, she lost three permanent teeth as a result of decalcification of the bone in her jaw. This has caused some problems with chewing and may indirectly affect digestion. To date Ms. Rippere has suffered one severe relapse during which her dosage required adjustment. Once again regulated, she reports that any over-exertion will bring on an exhausted collapse. This has affected both her occupational and social functioning.

d. Occupational Effects. Three years of, at best, marginal professional performance significantly retarded her career advancement. She reports that her cognition has improved and she has since doubled her writing output. However, because of her intolerance of physical exertion, she still loses a considerable amount of work time.

e. Social Functioning. Three years of illness coupled with the inability to tolerate much physical activity has negatively affected her social life. In her words:

> I used to be a fairly sociable, sometimes even gregarious introvert. Years of enforced solitariness, through being too tired to do anything in the evenings, have helped to lose the taste for out of hours sociability. Now even if I did have the energy to socialize with, I probably wouldn't expend it in this way; I've lost the habit of making chatty conversation and no longer feel I've got much to say, unless talking shop (pg. 127).

Singer (1974) called the above consequence of chronic illness "premature aging". From her study of patients with Parkinson's disease, she concluded that the sufferers of many chronic diseases engage in more sedentary activities, like reading and watching television, and are less socially active than their same-aged peers. The people she studied were less likely to be working or fully managing their households, and were less likely to enjoy a circle of close friends. Younger patients were relatively more likely to be isolated from interpersonal contacts than older people, whether this was the effect of others withdrawing from them or, conversely, their withdrawal from their peers. Charmaz (1987) and Strauss (1975) also noted that chronically ill people tend to be socially isolated and lead restricted lives.

It seems evident then that, in order to achieve a fuller understanding of any diagnostic entity, it is important to go beyond the medical concept of disease to explore, as well, the phenomenological experience of the

sufferer of that disease. "Illness is a critical aspect of being sick--what we experience affects what we do and how we feel. This is beyond--perhaps beside--the physiological and biomedical perspectives that dominate our thinking about disease and illness" (Conrad, 1987:27).

C. Theoretical Concepts

1. The Trajectory and its Management

From their extensive research into the temporal process of dying, Glaser and Strauss (1968) initially developed the concept of a dying trajectory, the perceived course of dying during which 'critical junctures' can be discerned. Rather than a linear pattern of purely objective stages of dying, critical junctures were conceived of as certain events that would occur during the dying process, but the timing of them and their order would vary. The authors were able, however, to outline several generalized trajectory types. The shape of a particular trajectory influences the organizational work of the hospital staff, ideally hospital staff attempt to fit their work to the individual patient's course of dying. The nature of the patient's disease, her personal and family life, and her hospital stay will together influence her illness trajectory but, also, will be affected by it.

The above theory was then applied to chronic illnesses, which can also be perceived as following a trajectory. Strauss (1975) developed a framework for understanding the

social and psychological problems that patients and their families must face. Seven problems of daily living were defined:

-preventing medical crises,

-controlling symptoms,

-following prescribed regimens,

-living with or preventing social isolation,

-adjusting to changes in the disease course,

-attempting to normalize interactions and life style, and

-obtaining the necessary funding for both treatment and living expenses (pg. 7,8).

Following from these key problems, he located:

(1) the basic strategies people develop to deal with them,

(2) the organizational and family arrangements that need to be made, and

(3) the consequences of those arrangements.

From this perspective, then, a chronic disease follows a predictable course, yet that course is individualized. Between identifiable critical junctures in a particular trajectory are identifiable phases of varied duration that proceed in either an upward, downward or stable direction, and that may be influenced by expected or unexpected contingencies. To manage each phase, the patient, her family and her medical helpers are required to perform varying types of work (Corbin and Strauss, 1984). If this

framework can be applied to this type of a broad classification of disease, i.e. chronic diseases, it seems reasonable to apply the same general framework to analyze the effects of a particular chronic syndrome, in this case hypothyroidism.

2. Additional Concepts from Related Studies

Several of Strauss's students have used his theory and method to describe the effects of specific chronic diseases, e.g. rheumatoid arthritis (Weiner, 1975), ulcerative colitis (Rief, 1975), emphysema (Fagerhaugh, 1975), renal failure (Suczek, 1975), and diabetes (Benoliel, 1975). Strauss stated that most chronic illnesses have a downward trajectory and the above studies exemplify this. In tracing the illness experience of a particular disease these studies begin at the time of diagnosis or at the disease crisis which precipitates the diagnosis. While there are phases of recovery and temporary (though sometimes very long) plateaus, the trend over time for these illnesses is downward toward eventual death.

Corbin and Strauss (1984) employed a grounded theory approach to examine the effect of collaboration between married couples in managing the chronic disease of one of them. To manage the illness trajectory four types of work similar to those identified in Strauss's theory of chronic illness were defined:

-symptom control and monitoring,

-preventing and handling crises,

-carrying out regimens, and

-preventing or living with social isolation.

Miller (1983) supplemented the above work types with other categories:

-modifying routines and lifestyles,

-maintaining a positive self-concept,

-dealing with role change,

-grieving with the losses associated with chronic illness,

-handling physical discomfort,

-maintaining hope despite an uncertain and downward course, and

-dealing with social stigma.

For couples to approach trajectory work collaboratively implies a degree of coordination, as well as the ability to negotiate and renegotiate tasks at different phases of the trajectory. Those couples who were most successful at collaboration were those who could openly communicate and talk through the work problem, and thereby prevent or resolve difficulties in trajectory management.

From the above literature review it appears that the experience of the sufferer of hypothyroidism has not been well researched. The present study applies Strauss's theory of a chronic illness trajectory and trajectory management to hypothyroidism as a means of gaining insight into that illness experience.

CHAPTER THREE

METHODOLOGY

A. Grounded Theory

Understanding an illness from the perspective of the sufferer necessarily entails asking those involved about their feelings, thoughts, experiences and life situations. The strength of such a subjective study relies on the methodology employed. This study uses grounded theory (Glaser and Strauss, 1967), an inductive theory generated from the systematic and simultaneous collection and analysis of data. Since data collection, coding and analysis occur throughout the research process, the method has also been called constant comparison, in which the emerging theory may, at any stage, suggest new codes and concepts for which data should collected. This circular process distinguishes it from the more linear pattern of traditional deductive research. Charmaz (1983a) pointed out several other differences:

- In grounded theory the research processes and products arise from the data rather than from a preconceived, logically deduced theoretical framework.
- Traditional quantitative rules of verification do not apply; researchers instead check their developing ideas against further observations and systematically compare their observations, often extending their research for comparison purposes into related settings and issues.

- Grounded theorists understand social life as a process and, as such, their goal is to produce theoretical analyses that, rather than providing a final interpretation, may later be transcended by addressing more and different questions to the data.

Steps in the grounded theory analysis of data (see Table 2) encompass the processes of coding, categorizing, memo-writing and memo-sorting to arrive at a core variable or basic social process (BSP), which is the central theme of the analysis. The initial data are coded line by line using "in vivo" or substantive codes derived from the subjects' vocabulary. The coded data are then grouped into categories by comparing them for similarities and differences and by asking "What does this incident indicate?" Theoretical categories are then compared and raised to a more abstract level, called theoretical codes, which conceptualize the relationship between the three levels of codes. Glaser (1978:74-82) lists eighteen families of codes to assist the researcher in theoretical coding. The primary one he refers to as the six C's--causes, contexts, contingencies, consequences, covariances and conditions. To give a simplistic example, in analyzing the statement that the hypothyroid sufferer feels tired, the researcher might ask:

cause	-What is the reason for her tiredness?
context	-What is the environment or setting of this tiredness?

TABLE TWO

STEPS IN THE GROUNDED THEORY METHOD

Table withdrawn for lack of copyright.

(source: Table 6-1, Hutchinson, 1986:119)

contingencies	-What are possibly unforeseen circumstances that affect the tiredness but are not logically necessary for its occurrence?
consequences	-What is the effect or result of her being tired?
covariances	-What other things appear to happen at the same time?
conditions	-What factors are necessary for this tiredness to occur?

The researcher next theoretically samples for those concepts and categories in which she is unable to answer

pertinent questions from the data already gathered. This means that subsequent data collection focuses upon answering these previously unanswered questions. When they can be answered and when the researcher can uncover no new information about a code, that code (or category) is said to be complete or saturated and further data collection can omit this category and concentrate upon other issues.

In this manner the data are minutely examined to look for patterns of similarities, differences, dimensions, and relationships. As new data are gathered they are similarly coded and compared with the previously identified categories and constructs. At every point in the analysis the researcher records in memos her theoretical ideas about connections among the data. In doing so, linkages are generated within the data and the researcher begins to fit the concepts together into an integrated theory.

From the data the researcher hypothesizes a core variable or basic social process that explains most of the behavioral variation in the data. Memos and theoretical codes are sorted according to how they relate to the core variable. When she has arrived at "a parsimonious set of integrated concepts" (Glaser, 1978:120), the researcher has discovered the framework from which the theory can be written.

Thorough grounding of the theory in the data in this manner ensures that the theory has the following characteristics (Glaser, 1978:4):

1. The theory *fits* the data. Categories are generated from the data, rather than the data being selected to fit prescribed categories.

2. The theory has *relevance*, i.e. it relates directly to the area of study.

3. The theory must *work*, meaning that "a theory should be able to explain what happened, predict what will happen and interpret what is happening in an area of substantive or formal theory." (Glaser, 1978:4)

4. The theory is *modifiable*. It can be extended and qualified to accommodate new data and variations.

This last characteristic, modifiability, is directly addressed by the present research. Strauss (1970) describes how previous grounded theory can be supplemented when the theory is examined and reveals certain phenomena that have been glossed over or to which the theory does not apply. These phenomena suggest additional categories for comparison with each other and with the original theory.

What Strauss appears to have neglected in his theory of chronic illness as a trajectory is that portion of the trajectory that occurs prior to diagnosis. This appears to be especially important in hypothyroidism, in which the pre-diagnosis segment of the trajectory may stretch over an extended period of time, and the sufferer is required to try to cope with uncomfortable signs and symptoms often without a clear understanding of their cause. Therefore, in applying the concept of a disease trajectory to hypothyroidism, it is important to examine the sufferer's experience prior to diagnosis and how that experience influences her subsequent management of the trajectory.

Before writing the report, the final methodological step in classic grounded theory methodology is a literature review, aimed at relating the grounded theory to existing sociological and other pertinent theory. However, because this particular study is launched from a previous theory, the method differs from classic grounded theory methodology in the timing of the literature review.

In 1970 Anselm Strauss outlined the process involved for discovering new theory from previous grounded theory. In order to extend the scope of an extant theory, one must first examine and understand the theory. Therefore, for this "emergent fit mode" (Chenitz and Swanson, 1986:18) of grounded theory, reviewing the pertinent literature and formulating a conceptual framework prior to beginning data collection are necessary. Once data analysis begins, it then becomes especially important to "bracket"[1] this conceptual framework in order to engage in open coding (Glaser, 1978:56) and allow the categories to emerge from the data, rather than forcing the data to fit these pre-set categories. Strauss states, "the researcher must be immediately sensitive to the new data and their potentials

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1 The term, bracket, comes from phenomenology, the theory developed by Alfred Schutz of how we construct meaning out of everyday experience. To gain insight into how she understands the world, a person must set aside what she already knows and then trace the process by which she came to know it. In trying to understand the experience of the person with hypothyroidism, it is important for the researcher to first set aside her own pre-conceptions of the phenomenon. For an introduction to the theory of phenomenology, see Craib, 1984:83-89.

for new coding, conceptual densification and integration" (1987:306). In all other respects the classic grounded theory method is followed and an expanded literature review remains necessary at the stage of data analysis so that the emergent theory can be linked with related existing theory.

B. The Study

1. Subjects

As the majority of hypothyroid sufferers are female, the study sample was limited to adult women. Twelve subjects were interviewed ranging in age from 32 to 68 years (a mean age of 48 years). Their age at diagnosis ranged from 25 years to 58 years, with a mean age at diagnosis of 40 years. This was slightly older than the Hudacin's (1985) survey's mean diagnostic age of 37 years. All except for one divorced subject were married and all have children ranging in number from one to seven each, an average of 2.8 per subject. Four of the women were in professional or semi-professional jobs. The rest were mainly clerical workers or home-makers. Several of the husbands were retired. The rest worked at occupations such as farmer, bus driver, carpenter and salesman. Socioeconomically, therefore, the subjects' occupations combined with those of their husbands placed them in the working, lower middle, and middle classes.

2. Recruitment

A non-probability, convenience sample was employed. A random probability sample is unnecessary for this form of multiple case study, since case studies need to be generalizable only to their theoretical propositions and not to populations or universes (Yin, 1984).

On May 17, 1989, I attended a meeting of the Edmonton Chapter of the Thyroid Foundation of Canada. The research project was outlined (see Appendix A) and, after assuring confidentiality and anonymity to the subjects, forms (see Appendix B) were circulated to solicit volunteers. A few more volunteers were found at the November 15, 1989 meeting. Altogether, seven of the subjects I interviewed were recruited from volunteers at these two meetings.

To initiate snowballing, I prepared a letter (see Appendix C) to be sent by subjects and other personal contacts to friends who have hypothyroidism. A return form (Appendix D) and a self-addressed, stamped envelope were provided. At the conclusion of each interview I asked the participants to pass the letter on to friends or family members with hypothyroidism. Three subjects were obtained in this manner. The final two subjects were contacted through acquaintances of mine at the University who were aware of my research.

3. Data Collection

The method of data collection was semi-structured, in-depth interviews, lasting from twenty-four minutes to one

hundred minutes. The average interview lasted fifty-six minutes. (See Appendix E for an outline of the interview questions.) These were face-to-face, tape-recorded interviews conducted privately in the subject's own home. The one exception was a lady who lived outside Edmonton and was interviewed in my home during a trip to the city. At the beginning of the interview the subject was informed of her rights in participating in the study and the interview consent form was discussed but not signed until after the interview (see Appendix F). This was a precaution to allow the subject freedom to withdraw her consent at any time during the interview. No subject did so. Typed transcripts of the interviews were numbered rather than named to ensure anonymity. In total, twelve subjects were interviewed and the twelve typed transcripts constituted the analyzed data.

CHAPTER FOUR

ANALYTICAL FRAMEWORK

A. Introduction

When the subjects in this study were asked to describe their experiences leading up to the discovery that they had hypothyroidism, two superficial similarities in their stories were quickly noted. In reconstructing their illness experience, they seemed to have difficulty pin-pointing the time when they first noticed that "something was wrong."[1] Then, for many, there was a considerable lapse in time until a diagnosis of hypothyroidism was made. Why, in this day of sophisticated medical science does the diagnostic process take so long, and what are the associated consequences for the sufferer of a hypothyroid illness?

A fundamental problem with this illness appears to be one of definition, stemming from the nature of the disease itself. Symptoms of hypothyroidism are often vague and subjective. They may appear gradually or in cycles, i.e. they may "come and go." Physicians acknowledge this fact when they observe that hypothyroidism can be difficult to diagnose.

From the sufferer's vantage point there appear to be two hurdles to overcome in defining her illness. Initially,

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1 Suchman's (1965) first stage of illness begins with the decision that "something is wrong". Similarly, Twaddle and Hessler's (1987) decision model of the sickness career starts with the realization of a change from normal and appraisal of that change as significant.

it can be difficult to recognize that "something is wrong" and whether that "something wrong" indicates illness or perhaps is the result of some situational factor. Then, once she has decided to solicit a physician's help, there is the problem of convincing him[2] of her illness. How this is accomplished demonstrates the classic process in symbolic interaction theory of negotiating shared meanings.[3]

The double-barrelled process of (1) the sufferer defining herself as ill and (2) negotiating with the physician for a diagnosis with which she agrees is the core category of this analysis. Glaser (1978:94) calls the core category the "main theme" of a grounded theory analysis.

When that "main theme" is a process involving a sequence of phases or stages, then it is called a BSP or basic social process. BSP's can be subdivided into two types: basic social psychological processes (BSPP) and basic social structural processes (BSSP). "An analysis can emphasize the BSPP or BSSP, or some mix of the two, depending on which process or which mix emerges as more

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2 The masculine pronoun will be used throughout this thesis to identify the physician since most physicians are male. This device will distinguish the physician from the (feminine) patient and avoid the awkward use of he/she, and him or her.

3 By taking the sufferer's perspective of her illness, this thesis embraces the theoretical paradigm of symbolic interactionism, developed by George Herbert Mead (1934). Social situations arise from ongoing interaction between people. Social order or stability results from the involved actors' achievement of shared meanings or interpretations of the situation. Social change occurs with continuing negotiation and renegotiation of the terms of the interaction.

relevant in the situation under study." (Glaser, 1978:103). This analysis focuses on a BSPP I have named "seeking validation".

I propose that "seeking validation" may be conceptualized as a basic social psychological process that adds to the previously described categories of trajectory management work for dealing with the seven key problems of illness in Strauss's theory of chronic illness. Strauss (1975:49) briefly touches on the problems encountered by the ill person in legitimizing her definition of her trajectory when that definition differs from the way others, including her physician, envision it. After interviewing subjects in this study, I concluded that "seeking validation" is an active process into which hypothyroid sufferers are thrust and that it is central to how they manage their trajectories.

Decision models of illness are not new (Fabriga, 1973; Suchman, 1965; Twaddle and Hessler, 1987). In such models the illness sufferer first chooses her actions based upon gathering subjective and objective data about her bodily sensations, i.e. symptoms, and then poses and tests hypotheses to ascertain the meaning and consequences of those symptoms. "Seeking validation" is a decision model of illness based on the sufferer's decisions for dealing with her symptoms and those made by her physician.

"Seeking validation" is also a grounded theory of illness behavior. Grounded theories are densely integrated

theories of social processes that strive to account for all the various social actions employed by individuals in order to achieve that social process. Any attempt to diagram so many different activities produces a confusing picture with arrows pointing in all directions. "Seeking validation" can be represented better as a typology in which the cells depict various levels of validation achieved.

B. Seeking Validation: A Typology

To validate something means "to confirm or corroborate; to substantiate or support" (The Compact Edition of the Oxford English Dictionary, 1971:3586). It appears from this study that the sufferer wanting to obtain treatment and help in dealing with her illness needs to ensure that others confirm her illness in the same way that she defines it.

From the sufferer's vantage point, two types of validation must occur in order to obtain treatment and, hopefully, relief of her symptoms. Firstly, she needs to validate her illness herself (internal validation). In other words she must recognize problematic changes in her body's functioning and interpret them as meaning illness. Secondly, she must secure confirmation of her illness from others (external validation). The ultimate outcome of this second step is usually a physician's diagnosis of a particular illness and his prescription of appropriate treatment. Combining the processes by which internal

validation and external validation are achieved constitutes the BSPP, "seeking validation."

By intersecting internal and external validation a typology can be constructed that illustrates how validation is achieved (fig. 2). One can divide the sufferer's

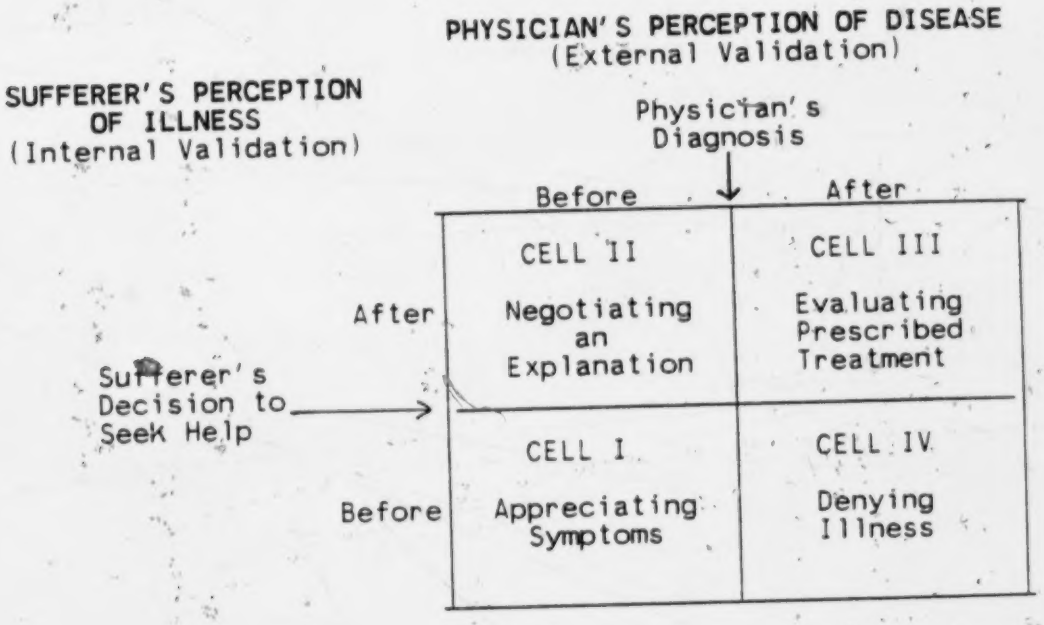

Fig. 2 A Typology for "Seeking Validation"

perception of illness (internal validation) into two phases at the point where the sufferer decides she needs help to alleviate her illness. Similarly, one can divide her physician's perception of her disease (external validation) into two phases: before and after the doctor's diagnosis. Cross-tabulating the sufferer's perception of illness as the vertical dimension with the doctor's perception of disease

as the horizontal dimension yields a four-cell typology. The cutting points, physician's diagnosis and sufferer's decision that she needs help to get better, become the critical junctures or boundaries separating the four cells of the typology.

Each cell in the typology represents a degree of validation achieved by the sufferer of hypothyroidism. Each cell is named to indicate the process that occurs within the cell:

Cell I Appreciating Symptoms:

Cell II Negotiating an Explanation

Cell III Evaluating Prescribed Treatment

Cell IV Denying Illness

Within each cell a principal action must take place in order for the sufferer to achieve the objective, i.e. the particular level of validation possible within that cell. The principal action can be broken down into types of validation work or strategies, i.e., how the sufferer manages to achieve the principal action. As well, there is a key obstacle facing the ill person who tries to achieve the principal action. This obstacle is composed of barriers that tend to prevent or delay accomplishing the principal action (Table 3). A brief descriptive outline of each cell follows.

TABLE THREE

ANALYTICAL FRAMEWORK FOR "SEEKING VALIDATION"

CELL	PRINCIPAL ACTION -Strategies	KEY OBSTACLE -Barriers	OUTCOME
I	Appreciating Symptoms -Historical Self-Comparison -Social Comparison -Symptomatic Self-Treatment	Difficulty in Interpreting Symptoms -Normalizing Symptoms -Self-Blame -Cyclic Symptoms -Family History	Uncer-tainty vs Certainty
II	Negotiating an Explanation -Use of Lay Referral System -Use of the Health Care System -Alternative Health Care -Triggers to Medical Consult	Difficulty in Describing & Legitimizing Illness -Denial and Discounting by Others -Impression Management -Labelling & Victim Blaming -Structure of the Doctor/Patient Relationship -Laboratory Tests	Delay vs No Delay
III	Evaluating Prescribed Treatment -Managing Medical Crises -Managing Regime -Symptom Control -Adjusting to Illness -Normalizing Life -Dealing with Social Isolation -Getting Funded	Treatment Doesn't Help -Misdiagnosis -Difficulties with Medication -Residual & Cyclic Symptoms -Different Trajectory Definitions -Poor Learning Resources	Satis-fied vs Not Satis-fied
IV	Denying Illness -Rejecting Treatment	Acknowledging Illness -Persistence of Symptoms	Percep-tion of Being Ill vs Not Ill

1. Cell I Appreciating Symptoms

Defining oneself as ill to the point of requiring help with treatment is the principal action that takes place in Cell I. Appreciating symptoms appears to involve two steps, the recognition that "something is wrong" and then the interpretation of those symptoms as illness. Through social comparison with others and/or historical comparison with the way she has felt in the past, a person may attribute these symptoms to illness. The main obstacle to such a conclusion is that symptoms of hypothyroidism are difficult to interpret because of their vagueness, subjectiveness and slow and insidious onset. Furthermore, barriers to the hypothyroid sufferer's defining of herself as ill arise from the ease with which symptoms can be discounted or blamed on something else, including deficiencies in the person herself. In the final analysis, deciding that she is ill confirms a degree of validation upon her symptoms of illness. This may be termed "self-validation".

2. Cell II Negotiating An Explanation

Unable to cure or control her symptoms alone, the ill person then actively solicits validation of her illness from others. This activity has been described as help-seeking behavior (Mechanic, 1978a). Opposing the principal action is the fact that, just as the symptoms of hypothyroidism are initially unclear to the sufferer, they are also difficult to describe and legitimate to others. Action strategies used by the sufferer to negotiate a shared meaning of her

illness must counteract structural barriers as well as those barriers that others erect, such as labelling or discounting and blaming the victim, in order for her to achieve "external validation" of her illness culminating in a definitive diagnosis.

3. Cell III Evaluating Prescribed Treatment

Complete validation of her illness entails acceptance of the doctor's specific diagnosis by the sufferer, cooperation in treatment and agreement between the doctor and patient that the treatment is curing the disease or, at least, alleviating her symptoms to some degree. The action strategies or validation work employed by the sufferer during this phase parallel those categories of trajectory management work that chronic illness sufferers use to control the daily living problems of illness as described by Strauss (1975). At the same time the sufferer is continually evaluating the effect of treatment. The key obstacle to achieving complete validation occurs when either the patient, doctor or both observe that this particular treatment is not helping. Barriers include misdiagnosis, difficulty regulating medication, residual symptoms and the lack of resources for learning about hypothyroidism. Achieving this ultimate level of validation will be especially problematic unless there is congruence between the patient's experience and the physician's expectations.

4. Cell IV Denying Illness

Cell IV represents the situation in which the physician has made a diagnosis and prescribed treatment but the patient rejects either or both. The doctor may describe her as non-compliant when the sufferer ignores his recommendations or modifies or stops treatment without consulting him. The patient's objective in denying illness is to regain some personal control over her situation. The obstacle that prevents remaining at this level of validation is encountered when symptoms persist, reappear or even exacerbate, and compel her to again admit to being ill.

5. Transition Among Cells

"Seeking validation" implies progressing from a state of non-validation to complete validation of illness. Such a progression depends upon successfully completing the objective of the principal action encountered in each cell of the typology. Depending upon the strategies she employs and the barriers presented to her, the legitimation outcome in any cell can transport the sufferer into any of the other three cells. If the typology is viewed as a grid then, at any particular point in time, the degree of validation received by the sufferer for her illness determines her location within the typology. An increase in validation moves her position toward the upper left corner; conversely "movement" downward and to the right would indicate decreasing validation. Although the cells are numbered to indicate their usual sequence, at least from Cells I to III,

progression is seldom completely linear and in many cases appears to involve a degree of bouncing around from cell to cell.

In the ideal case of hypothyroidism the sufferer would experience symptoms and decide that she is ill (Cell I). She would then go to see her doctor (Cell II) who would diagnose hypothyroidism and prescribe thyroid hormone, and the symptoms would abate (Cell III). In this ideal case Cell IV would not apply.

Unfortunately, the data collected for this study reveal that the ideal case appears to be the exception. Sufferers of hypothyroidism appear to move from cell to cell in the typology with neither ease, speed, nor a consistently positive direction. If the goal of "seeking validation" is a state of complete validation or agreement with the diagnosis and satisfaction with the treatment, it appears from this study that many sufferers of hypothyroidism fall short of ever *completely* achieving that goal.

The above typology illustrates the process by which women with hypothyroidism legitimate and receive validation for their illness experience. The purpose of the next four chapters is two-fold: first, to extend the typology into a densely integrated theory by revealing how it is grounded in and emergent from the data collected and, second, to relate the theory to relevant existing social-psychological theory.

CHAPTER FIVE

CELL I APPRECIATING SYMPTOMS

Perception of a change in either body sensations or functioning signals a person that she may be ill. Yet, such changes are seldom immediately interpreted as illness. Most changes, either biological or psychological, are ambiguous (Twaddle and Hessler, 1987; Leventhal, 1975) and it is the sufferer's interpretation of symptoms rather than their mere presence that determines her behavior (Leigh and Reiser, 1985).

A. Symptom Recognition

1. Initial Symptom

What was the first signal that "something was wrong" for the subjects in this study? For these women defining their initial symptom was not easy. Many had to recall years into the past. Because symptoms were typically subjective and vague, identifying the beginning of a lengthy illness was difficult. For some patients, cycles of exacerbation and remission confused the picture. Once a diagnosis was finally made, some subjects began to recollect long-standing symptoms and attribute them, rightly or wrongly, to thyroid disease.

One woman said that her first symptom was depression, but later she recalled an earlier episode of hair loss eight years before diagnosis leading to a suspicion of thyroid disease but negative laboratory results. Similarly, another

told of depression and erratic mood changes accompanied by a lack of energy and weight gain, but then remembered that when gaining weight nine years prior to her diagnosis, thyroid tests were done that were "slightly out". At that time she was told not to worry but no subsequent thyroid tests were done. The woman whose primary symptom was a feeling of choking was investigated for cardiac problems and a hiatus hernia but, when hypothyroidism was diagnosed, she recalled having felt cold from age 21 on.

For the purpose of this study I defined the earliest indication of possible thyroid failure as the subject's first self-reported symptom. Almost half (five) of the women identified tiredness as their first symptom of hypothyroidism. Three subjects were depressed; two had a visible goiter. Another reported a choking feeling like having swallowed "a big hunk of potato" or hard-boiled egg yolk. The twelfth subject's earliest complaint was exophthalmous, which refers to the protruding eyes that are common in Graves' Disease. She developed hypothyroidism after a thyroidectomy.

2. Common Physical Symptoms Before Diagnosis

Before being diagnosed, however, the women in this study developed many more symptoms. Merely listing the symptoms cannot convey their effect. Beginning to understand their impact demands reading excerpts from the sufferers' verbatim accounts.

a. Tiredness. From their own reports these women experienced, on average, 6.3 physical symptoms, ranging from two to ten symptoms each (Table 4). The most common complaint, a problem for ten of the women interviewed, was tiredness which they described as "no energy", "extreme fatigue", "exhaustion" and "overwhelming tiredness". A young mother related how she frequently fell asleep:

> December, I started to feel really tired and dragged out again, like I was just literally pushing myself... Um, I would fall asleep anywhere. I could be sittin' up and I'd just, boom, I'd be out. People kept tellin' me that, you know, I'd go to work and they'd say. "Didn't you sleep last night? You look, you know, so tired and everything."

The words of another woman, diagnosed at thirty-five years of age, describe how severe her tiredness was:

> I found that I was, I was so tired...to the point where I would actually come home at night and I would be too tired to eat. You know, I would just lie down on the couch, and not sleep, but just, I was just exhausted. I couldn't move another step. I couldn't get off the couch to come to the table....By two in the afternoon, I was just absolutely bagged at work. It was a real conscious effort to do anything.

Another, whose hypothyroidism followed the birth of her second child[1] told me:

> ...even just getting my whole, my house cleaned up was a major, it was just a huge thing to do. And to get my laundry done in one day was just, almost a huge

---

1 Flaherty (1984) found that auto-immune diseases often improve during pregnancy but rebound afterward. Jean Hudacin (1985) in her survey of the Thyroid Foundation of Canada found that, for one third of patients with spontaneous hypothyroidism, the time of onset was in the first six months following pregnancy. She concluded that pregnancy may trigger the development of latent or sub-clinical Hashimoto's, although Jansson (1984) points out that not all postpartum thyroid disease is auto-immune.

TABLE FOUR

REPORTED PHYSICAL SYMPTOMS PRIOR TO DIAGNOSIS

Symptom	Subject 01	02	03	04	05	06	07	08	09	10	11	12
Tiredness, Fatigue	*	*	*		*	*	*	*	*	*		*
Dry skin, Rash			*		*		*		*		*	*
Swelling, Weight gain		*			*	*		*	*		*	
Menstrual irregularity	*					*	*		*			*
Hair loss, Dry hair		*	*		*		*		*			
Constipation	*			*		*						*
Chest discomfort +		*						*			*	*
Puffy face		*	*		*					*		
Split nails				*		*			*			
Increased energy				*				*				
Heat intolerance	*			*								*
Cold intolerance	*			*							*	
Hypertension	*			*	*							
Decreased fertility				*			*					
Poor appetite, Nausea		*				*	*					
Exophthalmous		*						*				
Arm or leg pain		*							*			
Bradycardia		*										
Hypotension		*										
Hair prematurely gray						*			*			
Headaches				*								
Pale skin color				*								
Hoarse voice				*					?			
Thickened bones					*							
Bruising						*						
Freq. colds, infection									*			
Diarrhoea	*											
	01	02	03	04	05	06	07	08	09	10	11	12
	ab			ab		b	b	ab	a			a
				cd			c	d	cd			c

\+ described as choking feeling in chest, chest pain or palpitations
? described her voice changing
a reported symptoms consistent with hyperthyroidism at least once prior to diagnosis
b cyclic symptoms
c diagnosed as Hashimoto's Thyroiditis
d thyroidectomy done

> feat....I remember my legs were so heavy. Just going up those stairs to get those diapers just seemed so hard....I hated this house when I was sick 'cause, I thought, it's a four-level split. You have to go all the way down to the basement for the laundry.

b. Weight Gain and Fluid Retention. A reduced metabolic rate and a tendency to retain fluid causes people with thyroid deficiency to gain weight. One half of the women reported weight gain. In the words of one diabetic woman:

> And I thought I was just getting fat. And I was telling myself that I wasn't eating very much. I must be eating more than I should but I wasn't cheating on my diet that much. As a matter of fact I was actually coming down on my diet in some cases. And I still wasn't having reactions, which you normally do if you don't eat enough.

Five women reported having a puffy face (described by one lady as a "jowly look"), bags under their eyes, or other signs of fluid retention. A nurse described herself as looking like the textbook pictures of people with myxedema. Edema was a major problem for one woman:

> Retention of fluid was just phenomenal. I mean, I was just so swollen, I couldn't even wear my wedding band or anything, you know? It was, it was so bad. And, I'd ask the doctor there, I didn't know at the time it was my thyroid that was going wrong, and I said, "Can I have water pills? Look at me." I couldn't even get my rings off. I had a pair of loose pants and I was leaving the impressions of the seams on my skin and everything. He goes, "No, you can't have any water pills. I don't believe in them." I said, "Well, how do I get rid of this water?"

c. Integumentary Changes. Hypothyroid patients commonly notice dryness of their hair, skin and nails, and the subjects in this study were no exception. Several noticed their hair falling out and two reported turning gray

prematurely. Droopy eyelids prompted one lady to wear white eye shadow to make her eyes look bigger. Because she couldn't apply her make-up using a wall mirror, she instead propped a mirror on the table and sat looking down at it. One woman's doctor commented on her poor skin coloring. Another subject had excessive bruising. In most cases these symptoms, while seen at the time as bothersome, were only retrospectively seen as signs of illness.

The above changes in the skin and hair as well as generalized swelling combine to age a person's appearance. One subject, the diabetic woman, told of having a diabetic reaction. Her daughter called the emergency number. When the ambulance attendants arrived, they estimated her age based on her appearance as 56, although she was only 43 at the time.

d. Goiter. Often when the body experiences thyroid hormone insufficiency, it responds by enlarging the thyroid gland. Four subjects in the study described having a large or thick neck. One said that her neck was "like a rock" and, although it was painless, she was unable to turn her head. Another reported pain described by her as a sore or "burning" throat which, and on more than one occasion, caused her to lose her voice. This lady's goiter reached the point of:

> It was just really, really sore and I was having trouble breathing. If I laid down flat on my back, I couldn't breathe.

Three others had symptoms that might indicate thyroid enlargement. One had a chronic cough and was constantly clearing her throat. The other two described a lump in the throat or a choking sensation. These were long-standing annoyances that disappeared with hormone replacement therapy.

e. Sexual Dysfunction. Sexual dysfunction is not included in the usual medical textbook lists of hypothyroid symptoms, although the relationship between thyroid hormones and the reproductive system is well recognized. Four women spoke of their inability to become sexually aroused. The first subject to volunteer this problem described the effect this way:

> You don't. You don't. You have no urge for it at all, whatsoever. At least I don't.

A second woman concurred, saying that "something inside, isn't". She went on to explain that she had been on anti-depressants twice, and the first time that she had stopped taking them her sexual desires returned (whether this was prior to her hypothyroidism is not completely clear):

> ...but this time it never came back. It just sort of, I can't explain what it does, but it just sort of stayed put.

A third subject was sexually disinterested before her diagnosis but reports that her libido improved with thyroid hormone replacement. She said:

> ...'cause I didn't care whether there was a sex life or not, you know, 'cause I just had no desire at all. So that affects your relationship too.

The last subject to talk about lacking sexual feelings related it to her tiredness:

> I'm probably tired more often than he is...Like I say, let's get this over with and we can roll over and go to sleep. You know? I'd rather just have a kiss and a cuddle and that's it.

Langer and Scheer (1984) advise physicians to suspect hypothyroidism in both males and females with a diminished libido, although Soloman (1986) recognizes decreased libido only for males with hypothyroidism.

Five subjects reported either irregular or heavy menstrual periods. In general medical texts report that for women "the common results of hypothyroidism are menorrhagia and infertility" (Soloman, 1986:22). Thyroid hormone supplementation was once commonly used for infertility and menstrual irregularities. One of the women in this study reports having difficulty getting pregnant:

> So I went to my doctor, my gynecologist at that time, and he put me on thyroid medication...He said, "We'll put you on thyroid medication just to get you ovulating. Probably that's the problem." Well, that really worked. I had three children in quick succession after that.

She recalls taking thyroid medication for about six months, but doesn't remember "if I felt better or if I felt anything". In the next three years she had three children and, after the birth of the last child, was diagnosed with hypothyroidism.

f. Other Physical Symptoms. Although a variety of other symptoms were noted, only two: constipation and heart palpitations were reported by more than two of the women interviewed.

3. Common Psychological Symptoms

Some women experienced psychological symptoms (Table 5) that were, for them, more upsetting than the physical ones. Three-quarters of the subjects reported depression. Eight referred to themselves as feeling depressed and a ninth called her illness stressful and then described several

TABLE FIVE

REPORTED PSYCHOLOGICAL SYMPTOMS PRIOR TO DIAGNOSIS

Symptom	Subject 01	02	03	04	05	06	07	08	09	10	11	12
Depression	*	*	*	?	*	*	*		*			*
Labile Emotions		*	*	*	*	*			*			*
Cognitive Problems +	*			*	*		*					*
Insomnia				*					*			*
Lack of motivation				*		*						
Manic depression	*											
Flattened affect		*										
Anxiety				*								
Suicidal thoughts						*						
Can't get organized												*
Paranoia									*			
	01 #	02 #	03	04 #	05	06	07	08	09 #	10	11	12 #

\+ described as difficulty remembering, memory loss, difficulty concentrating
? reported feeling stressed and other symptoms suggestive of depression
\# treated by a psychiatrist or given psychiatric drugs prior to diagnosis

symptoms that can indicate depression, such as difficulty remembering, anxiety, lack of motivation, insomnia and labile emotions.[2] Four were treated with psychiatric drugs prior to being diagnosed with hypothyroidism.

a. Cognitive Difficulties. Several women told of problems with cognition, as in being "mentally not being quite as alert", or having "difficulty concentrating" or a "terrible memory." One woman put it this way:

> And the worst part I'd find is concentration. There were times I couldn't remember who, like I'd hang up the phone, what the other person really talked about. It got to the point I just couldn't even trust myself. And yet, otherwise I might snap out of it, I would really, I could really remember numbers. You know, and then something goes wrong that I can't remember. And it got to the point my husband wouldn't trust me because I'd hear something and I couldn't remember it. And-a, try reading at times and you just can't get yourself to concentrate.

b. Labile Emotions. Being unable to control their emotions was a common complaint as these four quotations show:

> I was so tired that I just felt like bursting into tears at work and I knew that I had three more hours to go, and so...[J.M.: Did you ever? Burst into tears at work?] Burst into tears? Um, I don't think I did. I was probably awfully close. And, like I really felt dumb. I felt depressed.

> Well, it was terrible because I would get so frustrated with my daughter, and she was two years old then. She would, they know something's wrong and she still wanted attention and I had the baby to look after. And I would just end up, sometimes, just screaming at her and she would be having, you know, a normal two year old type of tantrum, and then I would react, you know, over-react because I just couldn't handle it.

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2 For a summary of the symptoms of clinical depression see Ginsberg and Brown, 1982.

> ...like I say, I was going through very, very bad depressions at the time. I'd be driving home at night, crying. I didn't know why. I had feelings of nobody loved me; nobody cared about me. Um, my kids hated me as far as I thought. My husband, I figured that he was just using me. Like, terrible thoughts, really terrible.
>
> ...I would be happy one moment and the next moment I would be bawling my eyes out, for what reason I don't know. I couldn't explain.

An extreme case was a woman who remembers feeling suicidal:

> I would lie in bed and the only reason I would get up was because I had to, 'cause the kids, the baby was crying and my daughter. But I had absolutely no motivation, so it was probably the lowest point in my life. Like even, I even had thoughts of suicide at that time. Because I just felt like, I felt like I had nowhere to turn. I just felt so horrible.

c. Lack of Emotion. At the other end of the emotional spectrum was a lady who reported having a flattened affect with neither the energy nor the motivation to look for a lost pet.

> But I found that I couldn't get emotionally involved anymore with things. My emotions were kind of flat...also I didn't have the adrenalin flow. If something you love is gone, you're anxious and you're, you're really uptight and the adrenalin flows and you get extra energy. I wasn't getting any of that. From nowhere was I getting this.

She was also having marital problems. Yet her reaction to her husband's alcoholism was different from what she expected:

> I wasn't angry. I would cry but a normal crying for me, if I cry it's usually something...that is sad. I sob. But this crying was just, the tears would roll down my face, but inside I was dead. Yeah, it was an awful feeling, because I knew that I should be unhappier than I was.

d. Insomnia. Insomnia has been reported to occur before diagnosis (Hall et al., 1982). Hall (1983) mentions that sleep disturbance can last for several weeks to months following thyroid hormone replacement. Four subjects described problems with sleeping. All of them report cyclic symptoms and three have Hashimoto's disease.

I asked them to describe their sleeplessness. One says she goes to bed and starts worrying about getting to sleep and "just can't turn it off". Another says:

> I sometimes get to the point where I dread to go to sleep [bed] because I know I'm not going to sleep.

There appears to be no pattern to her sleeplessness: sometimes she doesn't fall asleep until early morning, sometimes not at all. Sometimes she wakens at three o'clock and is not able to get back to sleep. She was unable to relate her sleeplessness to times of being either more "hyper" or more "hypo". The third woman thought she was unable to sleep when she was hyper but "my doctor's been telling me now, he says that when you're hypo it will affect you the same way."

The above evidence of physical and psychological symptoms describe how the subjects in this study remember feeling before they were diagnosed. At the time, many failed to recognize the symptoms as illness, at least initially.

B. Symptom Attribution

Healthy people commonly experience many of the above symptoms. Therefore the ill person may ignore or tolerate them as ordinary feelings. Unless symptoms are severe or incapacitating people tend, at least initially, to justify or "normalize" (Mechanic, 1978a) them, by assuring themselves that many other people have similar experiences.

Such familiar everyday sensations may only be attributed to illness when they increase in frequency, severity or become more visible to others. Often only when they disrupt ordinary social functioning and interfere with a person's work or social activities will they indicate illness. Mechanic states that "any set of symptoms may be evaluated by the extent to which they disrupt normal functioning, their visibility to others, their perceived seriousness, the extent to which they elicit embarrassment, the extent to which treatment is perceived as effective and so on" (1978a:274).

Tiredness, gaining weight, changes in the skin and hair, and emotional upsets: all these are ordinary, everyday sensations and not readily indicative of sickness. How then does one arrive at the conclusion that she is ill and needs help to get well?

C. Strategies for Self-Validation

The subjects in this study used various ways of ascertaining whether their symptoms were actually signs of

illness. The strategies they employed are historical self-comparison, social comparison, and symptomatic self-treatment.

1. Historical Self-Comparison

At this early stage of illness, a common way to evaluate symptoms was to compare the way she feels now with how she remembers being. This strategy was useful when a person was gaining weight, or unable to wear wedding rings that used to fit, or when her hair appeared to dry out. These were readily measurable changes. A more subjective symptom, being tired, made sufferers wonder if they had the 'flu' or if they might be pregnant again. In many cases the subject summed up her state as, "This isn't me" or "I'm normally not like that."

2. Social Comparison

An individual is driven to verify personal opinions and abilities by comparing them with the opinions and abilities of others (Festinger, 1954). This basic premise of social comparison theory is especially important in the absence of objective ways to measure changes in opinions or abilities. Change in one's body is a subjective sensation that invites corroboration so that the sufferer can judge its "correctness."

Social comparison may occur early in the symptom attribution process, long before traits become defined as

symptoms as this quotation indicates:

> ...as a teenager I always envied my sister because she was so alert, and especially in the mornings. She would get up just as soon as the clock rang and she was off to work or to school, whereas I always dragged behind. And I used to get annoyed at myself, but I was so lazy I couldn't figure out what was wrong.

On the other hand social comparison may be used to confirm a self-diagnosis of illness. A nurse who was quite sure that she had hypothyroidism compared her face to textbook pictures of a myxedema patient.

Schachter (1964) theorized that physiological changes produce an internal state of arousal and, unless there is a clear and appropriate explanation for the changed state, people use external or situational cues in order to label the emotion elicited. Where the situation is completely inappropriate to the feelings elicited, the individual might decide that she was sick (Schachter and Singer, 1962; Schachter, 1964). This point is well illustrated by one subject who initially attributed her exhaustion to situational factors, problems with her teen-aged son and the anticipation of moving to another province and finding a new job. When her situation resolved (the son was doing better; they were settled in Edmonton; she had a job she liked), she was feeling worse instead of better. At that point she decided she was ill and should consult a doctor.

3. Symptomatic Self-Treatment

For most people, recognizing that symptoms indicate illness fails to lead immediately to help-seeking behavior

(Twaddle and Hessler, 1987). Unless the symptoms are severe, or the illness is perceived as serious, most will try self-treatment with patent medicines or culturally known remedies. Self-treatment of early hypothyroid symptoms, especially the physical ones, is common as the following quotations show:

> I lost a big chunk of hair off the back of my head. Smooth as a baby's bottom. Nothing there. About that size [indicates an area about 2.5 inches in diameter],...I just got up one morning and I had a handful of hair and I [said], "Huh?" And it first started off like that. It was getting bigger and bigger and I thought, "Geez, I better go get my hair cut. I've got something terrible in it." I started using all kinds of strong shampoos. Got a louse shampoo.
>
> And my skin was really dry, you know. I couldn't wear my rings because I would get such a dry, sort of rash underneath them that it would be painful. So I didn't wear my rings. And-a, I started using lots of conditioners and stuff like that.
>
> Oh, I tried dieting. I was on, at one point I put myself on an eight hundred calorie diet for months, and I gained weight instead of losing.

One woman was sure that she could overcome depression and tiredness with hard work and exercise:

> And I started to think, "Okay, this is mind over matter," and I would try to get out jogging and doing all kinds of physical activity and just really having a lot of things planned. And I went back to work, part-time, and it just wasn't working, you know. I was still exhausted...and I just couldn't seem to bring myself back up, but what else, you know, I thought, "What else can I do?"....And I just really, really worked hard saying that I've got to get, build myself up. I was washing windows one weekend and digging potatoes and really working hard and I ended up going to work and I had a, I passed out and I had a, like, a seizure.

Often, it is only when self-treatment fails, or when the symptoms persist or increase in spite of self-treatment, that people will begin to look for advice from others.

D. Barriers Against Self-Validation

If the basic process necessary to achieve self-validation of illness in hypothyroidism is the appreciation of symptoms, then the key obstacle as described above is the difficulty of interpreting those symptoms. The vague and subjective quality of the symptoms and their slow and insidious onset, coupled with the personal threat inherent in succumbing to illness, erects barriers that frustrate the achievement of symptom perception and attribution. Several barriers identified in this study are the tendency to discount or normalize symptoms, to have symptoms that are cyclic in occurrence, and to negatively label herself or blame herself for her illness. Contrary to what one might expect, having a family history of thyroid disease was not helpful for these women for self-defining their illness.

1. Normalizing Symptoms

Because illness implies personal threat, individuals may deny or normalize their symptoms (Mechanic, 1978) as a defense mechanism, in an attempt to restore a sense of order and meaningfulness about themselves and their world. Symptoms become redefined "so as to minimize the threats to one's assumptive world" (Janoff-Bulman and Timko, 1987:8).

Normalizing is easiest for those symptoms that are long-standing and relatively stable. The subject who waited the longest between her first symptom and the initiation of treatment says:

> I went through a really bad time there in those, oh, good thirty years. Really a bad time. And I didn't know. You don't know what's happening. You think this is the way you're supposed to live. So you just don't say anything. This is the way I'm supposed to be. You don't know and you just take it for granted that this is it.

While denial may be a defense mechanism, an attempt by the individual to maintain control, it may only serve to increase her stress in the long run. Lefton (1984) observes that denial forces the ill person to try to maintain her normal lifestyle and anger and an exacerbation of the disease process can result.

Physical changes are often rationalized. Symptoms may be threatening when they are attributed to the individual's situation. For example, one woman discounted her dry skin and hair because she had moved from a coastal area to the prairies. Symptoms may also be ignored in the face of other more important activities (Mechanic, 1978a), or they may be seen as resulting from those competing activities. In this study tiredness was attributed to studying too hard, to the strain of raising several children, or to juggling a home and job, etc. While it is commonly assumed that women with several competing roles are prone to stress and ill-health, studies have shown that women balancing several roles are

not necessarily less healthy than others (Verbrugge, 1983, 1985; Kandel et al., 1985).

Being aware of illness in others may prompt a person to monitor herself for signs of illness and so speed up the symptom attribution process (Leventhal et al., 1982). It may also prompt misattributing those symptoms to other diseases. Two subjects assumed they had cardiac problems. In one case her fear sent her promptly to the doctor. In the following case fear of the consequences of heart disease may have delayed help-seeking[3]:

> Thyroid was the last thing I thought I had, with my husband having heart problems. I had kind of a choking feeling in the chest....I'm not one that goes to the doctor that quickly and I took maybe three months. You know, I kind of thought maybe its indigestion, maybe something I ate.

As the above quote also shows, new symptoms may be misattributed to an already familiar disease. While new symptoms are usually more salient (Mechanic, 1978a) than on-going or recurring ones, an existing frame of reference for illness influences how symptoms are perceived. Leventhal et al. (1982) state, "Representations of illness problems will be in error when the problem departs from the individual's past concrete experience with illness" (pg.68) To

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3 Janis (1967) proposed that there is an optimal level of fear arousal for initiating adaptive behavioral responses. Perceived threat that is less than the optimal level will influence behavior in a maladaptive way, causing people to deny the threat and look for blanket reassurance of no danger. Heightened fear, in contrast, prompts tension, jittery reactions, extreme defenses and cognitive reconstruction of the event responsible for the fear. For this woman, her husband's severe heart condition may have served to increase her own fear of having a similar illness.

illustrate how former illness problems can color one's attribution of symptoms, one subject blamed her memory loss on her long-standing diabetes:

> At some points I thought it was my diabetes. I thought, "Okay, you've had so many reactions, you've blown part of your brain."

Cultural concepts can also be used to explain illness (Leventhal et al., 1982). An example is the expectations we have of aging. One subject ascribed her inability to think of the right words to express herself and her poor memory to getting older. Another assumed at first that her tiredness resulted from heavy menstrual periods that were just a normal signal of menopause.

Mechanic (1978a) contends that people are more likely to rationalize or normalize psychological symptoms than physical ones. This, he says, is because of the stigma and negative cultural attitude attached to mental illness and the problem of discriminating between those with psychiatric illness and those with idiosyncratic personalities. With hypothyroidism, the sufferer appears to discount both physical and psychological symptoms equally. One explanation may be that many of the physical symptoms carry a stigma and elicit cultural disapproval. Some examples are obesity, swollen facial features, imperfect skin, dry hair and split nails. In a similar way, chronic tiredness reflects negatively upon the individual's personality.

2. Self-Blame

A particular type of symptom misattribution is related to discounting but occurs when the individual, instead of attributing her symptoms to external events, turns her attention inward and interprets the symptoms as indicating a deficiency in herself. Self-blame is a form of illness denial allowing the sufferer cognitively to escape from becoming a victim of disease and, seemingly, to retain some degree of control or personal autonomy over her situation. Blaming herself for being lazy, a bad parent, or weak and unable to resist the temptation of eating too much (as some subjects did) implies that she has, or feels that she should have, the power to reverse those symptoms.

On the other hand, negative self-labelling is probably a self-limiting solution. She is unable to reverse her illness and eventually, the symptoms prevail. For example, her tiredness persists, she continues to neglect or lash out at her children, and diets fail. Ultimately, she is forced to confront and reinterpret her symptoms.

3. Cyclic Symptoms

When the hypothyroid person's symptoms appear to "come and go" then defining herself as ill is even more difficult. One woman described her off-and-on dry skin rash:

> I had this rash on my neck and I'd be scratching it and it'd go partly away, then it's come back. The it broke out on the leg. And I had this for years on the leg. Everybody'd ask me, 'Did you burn yourself?' I couldn't figure with this rash. So when it left here it went to my elbows. And it would just go away then it'd flare up again. [Then with the informed hindsight

of now knowing her diagnosis she went on to say:] And I think it flares up as soon as I go hypo.

More than half the subjects told of periodically changing symptoms that could indicate a fluctuation in thyroid function. Several clearly showed signs of hyperthyroidism at times.

> ...maybe my thyroid, also, historically, has gone down and then has probably gone up somewhat, so that there was at least one time in my life where it seemed like I was, perhaps, somewhat manic in the sense that I had more energy than I ever had before and I didn't have all the typical manic, in the mental health perspective, problem, but I had some of the other typical things, like I had diarrhoea, you know. I was warm, which I normally am not.

Others described swinging between being hyperthyroid and hypothyroid, or from a state they defined as normal to hypothyroidism. The thyroid would appear to go into periods of failure and then seem to kick in again.

In the beginning the cyclic nature of hypothyroid symptoms probably delays the decision that one is ill and needs help to get better. When symptoms are in remission there is no longer a need to cure them. On the other hand, as cycles repeat themselves, one may be more inclined to define them as signs of illness. Normalizing them or attributing them to outside factors becomes more difficult.

> I would get depressed and then get out of the depression and there was not always a cause for that sort of thing.

This same woman goes on to describe the emotional effect of this unpredictability.

> Academically, I would be doing really fine and then I'd just sort of have a slump. My whole system would seem to just go down, you know, physically, and mentally not

> be quite as alert and I was not very pleased with all this, of course.

Cyclic symptoms can destroy a person's self-esteem. An autobiographical account of Parkinson's Disease highlights the "on-off" characteristic of capricious worsening and easing-up of symptoms as particularly difficult, stating that it makes life unpredictable and erodes one's sense of self-confidence and continuity (Lefton, 1984).

Changing symptoms may make it more difficult to know whether stressful psychological symptoms are a part of the biological process of a disease or a reaction to it. In any case they are part of the illness experience and add to her discomfort.

> So I had both ["hyper" and "hypo" periods]. I don't know how to describe it. I didn't know what was going on then. I didn't know what was going on. Very nervous, you know....Then you get nervous, and you can get very moody. Be up high one minute and then, the next, you just don't want anybody to talk to you.

4. Family History

Thyroid disease tends to cluster in families (Beall and Soloman, 1973; Dahlberg and Jansson, 1983; Evered et al., 1973). One would expect people with a family history of thyroid disease to be alerted to the possibility of a developing thyroid condition. As Leventhal et al. (1982) state, being aware of illness in others tends to focus a person's attention on changes in his own body. Such does not appear to be the case for these subjects. Half the study's respondents had a positive family history of thyroid disease (Table 6). One subject reports that her older

TABLE SIX

FAMILY HISTORY OF THYROID DISEASE

Subject Number	Family Member Diagnosed Before Subject Relation	Diagnosis	Family Member Diagnosed After Subject Relation	Diagnosis
01	sister	Hyper->surgery ->Hypothyroid	sister sister mother	Hashimoto's Hypothyroid Hypothyroid
02	aunt?	N	son	Graves'-> radiation-> Hypothyroid
03				
04				
05				
06	mother	Hashimoto's		
07	G'mother	Goiter	mother sister?	Hypothyroid N
* 08	uncle +	likely Graves'	sister sister son?	Hashimoto's Hypothyroid N
09			mother?	N
10			sister	N
* 11	uncle + sister sister	likely Graves' Hashimoto's Hyper->surgery Hypothyroid		
* 12	uncle + sister	likely Graves' Hyper->surgery Hypothyroid	sister daughter?	Hypothyroid N

* Subjects are sisters.
? Thyroid disease suspected by subject but not diagnosed.
N Diagnosis not known.
\+ This man was described as having protruding eyes and as displaying behavior consistent with both hyperthyroidism and hypothyroidism.

sister was living in Europe and was diagnosed there but "it was never disclosed."

Another subject suspects an aunt of having hypothyroidism. This lady had fine textured, snow-white hair before the age of twenty-five. She explains her family's proud character and attitude to illness this way:

> ...they won't go into who was sick and who wasn't....I don't think they know because nobody would tell them. If somebody was sick they would hide them away. Don't want them to think there's anything wrong with your family...and they seem to think that you want to find out so you can blame somebody.

An element of stigma (Goffman, 1963) attached to familial disease in some cases may mitigate against its early recognition in family members who subsequently develop the illness. Where stigma is attached to an illness, then social comparison may lead not to a quicker diagnosis as expected but instead, to denial of problems and, hence, delay in the diagnosis.

Hypothyroid symptoms such as weight gain and lethargy may be attributed to obesity, itself a stigmatized condition. It is even more likely that the psychiatric symptoms and behavioral manifestations are perceived to be the "blemishes of individual character" (Goffman, 1963:4) that set the sufferer apart from the mainstream. Three subjects were sisters with an uncle who had severe hypothyroidism and one of them described him thus:

> And he had a very serious case of it...like he was called, you know, he was so slow. They used to call

> him...like he was called retarded at one point because he was so slow.[4]

Knowledge of their uncle's illness didn't seem to speed up diagnosing these sisters. The first sister was diagnosed when she was twenty-nine, but probably had symptoms that were unrecognized at a much earlier age. One of her sisters described the first sister as a teenager:

> I can compare her to myself. It's so hard to get her out of bed. It always was. When she went to high school, it seemed her friends were waiting at the front door and here I was in the bedroom getting (her name) up and helping her to dress...I think she really went through a lot. Yeah...too bad, but none of us knew what it was. You know, we could see her action and we thought, "Well, she's just odd."

Known thyroid disease in other family members may even lead to rejecting thyroid disease as a possible cause of one's own illness. As Asher (1949) observed, myxedema has many diverse symptoms that are common in other illnesses, but not one is constant or definitive of hypothyroidism. When asked whether she had ever suspected her own thyroid disease in light of her sisters' problems, the second sister to be diagnosed said:

> No, because my sister had it and my uncle did but they were hyper. You know, with the bulging eyes.

When I asked the third sister the same question she replied:

> I have family, yes, both sisters had it before I, and yet I didn't, I didn't associate it at all because of, they never had this kind of a choking feeling in the chest.

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4 This man is also described as being hyper and having bulging eyes. He must have been both hyperthyroid and hypothyroid at different times. Graves' Disease and Hashimoto's Thyroiditis are probably different ends of a spectrum of auto-immune illness (Jaffiol et al., 1983; Wilson and Jefferson, 1985).

Similarly, the fact that one woman's grandmother had had surgery for a "very big goiter" was no help in defining her own hypothyroidism, which caused tiredness and depression.

A final subject had both a mother with Hashimoto's and a personal history of non-symptomatic goiter. When she developed symptoms postpartum she didn't connect the two:

> ...it just wasn't something that was in my mind, I think, because so many other things were going on right at that time.

In all, six and possibly seven of the twelve subjects had a positive family history but, in not one case, was it helpful for the subject in attributing her own symptoms to illness. This may be due to the stigma attached to thyroid disease, a lack of congruence between the symptoms experienced by people with either the same or different forms of the disease, or just a general deficiency in popular knowledge about thyroid disease.

Whether increasing the public's knowledge about thyroid disease will reverse this finding remains to be seen. Perhaps it will. Generally, people are becoming much better-informed consumers of health-care. This study's subjects are now, on the whole, well aware of their disease process and its tendency to be inherited. Six have relatives who developed thyroid disease following their own diagnosis; four presently suspect that a direct relative may be hypothyroid. Even though not directly questioned about a concern for family members developing thyroid problems,

almost everyone interviewed believes in the importance of family members, especially their own children, being aware of thyroid disease and undergoing periodic tests.

F. Cognitive Factors

What I have called barriers against self-validation of a person's illness may be explained theoretically as cognitive reconstructions of the symptoms in order to avoid or cope with the threat of illness. A latent result of misattribution of illness is to spare the individual from becoming a victim of disease. Janoff-Bulman and Frieze (1983) explain that to submit to victimization threatens three major assumptions about the world. These are:

1. the belief in personal invulnerability;
2. the perception of the world as meaningful and comprehensible;
3. the view of ourselves in a positive light (pg.3).

When recognizing that symptoms mean illness, Mechanic (1978) has said that a person's level of self-esteem (i.e. assumption 3 above) appears to be linked to their sense of invulnerability (assumption 1 above). Antonovsky (1987) incorporated the above concepts into a "sense of coherence" that allows people to locate themselves on a continuum between "health-ease" and "dis-ease." A person is thought to be better able to mobilize resources for resistance against stressors which she sees as challenges worth resisting and when she interprets life events as "structured, predictable and explicable" (Antonovsky,

1987:19). Such a person is said to have a strong "sense of coherence", i.e. has confidence that life is manageable, meaningful and comprehensible. Her illness symptoms are more likely to be correctly identified and dealt with appropriately. On the other hand a person with a weak sense of coherence is liable to deny her symptoms.

In relating how their hypothyroidism developed most of the women in this study described their lives in the face of their symptoms as anything but manageable, meaningful and comprehensible. Instead, the changes they experienced were difficult to explain, unpredictable and riddled with uncertainty.

G. Outcomes of Cell One

1. Uncertainty

An uncertain event incorporates at least one of the following eight dimensions: vagueness, lack of clarity, ambiguity, unpredictability, inconsistency, probability, multiple meanings and lack of information (Norton, 1975; cited in Mishel, 1981). Unpredictability refers to uncertainty about how things will change and probability refers to a change that is expected, but for which the timing is unsure. With the possible exception of probability the symptom experience in hypothyroidism appears to incorporate them all. Mishel (1981) hypothesized that where uncertainty is high in illness, intrapsychic modes of coping will be fostered in place of direct action and

information seeking. Such cognitive reconstructions of events contribute to the length of time it takes many women with hypothyroidism to decide to seek help for their illness.

2. Transition from Cell I

In hypothyroidism the pathway to a personal decision that one is ill and should seek help is complex and often lengthy. After recognizing biological and/or psychological changes in herself, and evaluating the importance of those changes, she decides:

1. I am not ill;
2. I am ill but can treat myself; or
3. I am ill and need help to get better.

Any of these decisions will accomplish some degree of self-validation and will affect a person's place in the typology. The individual who makes decision one has no more need for validation and effectively "moves" out of the typology to the bottom right hand corner. If she makes decision two, she remains in Cell I and initiates self treatment. If the treatment is successful the symptoms abate, validation is achieved and she also "moves" out of the typology. In these cases, and if in fact she has hypothyroidism, the above decisions are likely to be temporary and sooner or later symptom perception and attribution will begin anew. In the ideal case already described the individual makes decision three, at which point she "moves" into Cell II.

Those who are unable to make a decision will also relocate to Cell II. "When doubts arise about experience a person may turn to others for clarification and validation" (Leventhal, 1975:128). In fact, the more uncertain a person is about her illness, the more important it is for her to consult others (Stimson and Webb, 1975). In this situation it is unnecessary for her to self-validate her illness first. Instead, social validation of her illness as in Cell II becomes a method for achieving self-validation.

CHAPTER SIX

CELL II NEGOTIATING AN EXPLANATION

Social comparison also underlies achieving external validation for her illness as the sufferer engages in "help-seeking behavior" by searching for information, acceptance, and advice from others. Freidson (1961) has described how patients utilize a lay-referral system that often leads to professional consultations. Depending on the advice received from lay referrals the sufferer of an illness may consult one or more physicians or she may consult persons who, in the judgement of western allopathic medicine, practise alternative forms of health care. In addition, the sufferer may respond to one or more of the triggers outlined by Zola (1973) that persuade a person with symptoms to seek medical care. Consulting the lay referral system or doctors in the health care delivery system, utilizing alternative health practitioners, and responding to triggers constitute the strategies employed by the women whom I interviewed in their search for an expert definition, i.e. diagnosis, of their illness.

A. Strategies for Expert Validation

1. Use of the Lay Referral System

The primary strategy used by these women to confirm the meaning of their illness and eventually secure a professional diagnosis and treatment is to consult the lay-referral system. Freidson describes a network of referrals

extending "from the intimate and most informal confines of the nuclear family through successively more select, distant and authoritative persons until a 'professional' is reached" (1961:146). Whether and how directly the sufferer reaches the physician depends on the culture and education of the referring participants, their understanding of the causes of and cures for illness and their past experiences with medical practitioners.. Lay persons who confirm her illness and offer advice and reassurance confer a type of "provisional validation" (Suchman, 1965) upon her illness experience.

The interviews in this study were not structured to reveal subjects' pathways through their individual lay referral systems. Nonetheless, it is evident from the comments made that a variety of contacts were consulted and that lay individuals also offered unsolicited advice. An example follows:

> But for the last couple of years before I was diagnosed my husband was extremely worried.

A colleague at work who had know this women some years previously remarked on her change in weight:

> You're not the [same] person; you're not like you were before. What's the matter? This is not you. This is not normal. I remember you as a tiny little person.

Even comments like these, while not providing advice about solutions, provide a measure of validation by confirming the individual's definition of herself as ill.

Another lady said that neither she nor her husband had noticed her swollen neck despite her recurrent sore throats,

colds that she had treated with home remedies and several trips to the doctor. One day a co-worker commented:

> But one of the girls at work who hadn't seen me for quite a while, I walked into work and I sat down and she looked at me and she goes, "My God!" she says, "Your neck is just swollen." And I was going like this [demonstrates how she felt around the front of her neck] and I thought, "You know, I don't have a neck anymore."

A few days afterward she underwent a thyroidectomy.

When another subject mentioned her tiredness to an acquaintance, she was referred to a physician interested in yeast infections. He diagnosed her hypothyroidism.

Participants in the study were asked whether they or anyone else had suspected thyroid disease prior to the actual medical diagnosis. One said that a neighbor had suspected diabetes. This was subsequently ruled out but the doctor didn't offer any alternate diagnosis.

In three cases a lay diagnosis of thyroid disease was made. A nurse diagnosed herself long before she was able to convince a doctor to treat her. A second woman who described treating her hair for lice was alerted to the possibility of thyroid disease by a male hypothyroid co-worker who noticed her hair loss:

> And then finally one of the guys at work said to me, "You know, you lose hair when you have a thyroid problem." He had been hyper and they got him hypo years ago.
> And so I said, "Okay, I'll make a doctor's appointment." So I walked in and said, "I've got a thyroid problem and my hair's falling out." And he said, "No, no. You don't have a thyroid problem."

She reports undergoing periodic thyroid testing for years before a diagnosis was made.

The third woman to be diagnosed by a lay person was hyperthyroid when she was diagnosed by a cousin who was a pharmacist and who recognized her exophthalmous. She was immediately diagnosed by her doctor, received radioactive treatment and surgery and "was fine" for awhile. In this instance the subject had recognizable objective signs of disease and received professional validation very quickly after a lay diagnosis.

Sometimes a lay referral serves to confirm the sufferer's illness experience. Sometimes it leads directly to the doctor's office. Sometimes a diagnosis is made and treatment is initiated. At other times the doctor and patient fail to concur when evaluating her problem.

2. Use of the Health Care Delivery System

For many people, the first physician consulted makes a diagnosis and prescribes treatment, however, when a physician's diagnosis or the lack of one fails to agree with her own evaluation of her symptoms, the patient may bow to the power of his expertise and accept his opinion or, faced with persistent symptoms, she may adhere to her own opinion. In the latter situation, one option at her disposal is to seek a second opinion or a third. Some of the women in this study needed to resort to "doctor-shopping", consulting a series of doctors in active pursuit of someone who would interpret their problems as they did.

Describing how she tried to convince her family doctor for five years about her physical illness, the nurse who diagnosed herself recalls:

> But that was a depressing (time) and then with the disease making you depressed and with no one believing you it becomes very traumatic and you reach almost a crisis. And this is the point that I had gotten to when I started going from doctor to doctor until someone would believe me...I was trying to get a referral to an endocrinologist and, probably, if I hadn't gotten one fairly soon, I would have appeared at an emergency room about midnight--throwing hysterics! I believe that works quite well.

Reflecting on her own experience another woman advised others:

> And I think also that if you're not quite happy with it, you should just get out there and dig and find another doctor because, you know, they keep telling you it's just, or in my case, that it was being a Mom and all that. You just don't have to buy that. And it's very difficult to go out and find another doctor, or to doctor-shop. But keep pushing until you find something that is going to satisfy you that you're feeling better.

Retrospectively, another blamed her lengthy pre-diagnosis suffering on her lack of assertiveness and on staying with a familiar physician.

> I'm not one to run from doctor to doctor but you gotta learn. This is a big lesson I learnt. You can't put your whole trust into one doctor...That's very foolish because now I know, being older, I keep stressing to my children, now if you're not...satisfied. You can't be running around from doctor to doctor. I don't believe in that. Get a second, get a third opinion. Not me. Oh no, I didn't want to hurt his feelings. I didn't want to hurt his feelings that I was going to go to another doctor. Me? Go to another doctor?

Conventional medical wisdom may view doctor-shopping as dysfunctional, holding that [illegible]ily physician who sees a patient on an ongoing basis is more likely to pick up changes than one who sees a person sporadically or only

once. However, the doctor in a long-standing relationship may have pre-formed a schema[1] for his patient and may fail to notice gradual changes. Where this is so, increasing the number of individual doctors encountered will increase the probability of securing a diagnosis. For four subjects the hypothyroidism was diagnosed by a doctor they had never seen before as these quotations show:

> But he, being a family doctor of mine of thirty-seven years, he should have known. It took another doctor that never seen me in his life to spot it right now.

> I finally went to about four different GPs in a period of about three months. The last one took one look at me and said, "Ye Gods!" then sent me to an endocrinologist.

One subject was diagnosed by a gynecologist consulted just because "at my age I should go see a gynecologist." This lady had had a thyroidectomy ten years previously, but had never been given a thyroid supplement. In the interim her physician and several emergency departments had been prescribing Fiorinal[2] for severe migraines and she had had a hemorrhoidectomy that she blames upon relentless constipation. The constipation and headaches resolved when she began taking Synthroid.[3]

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1 Cognitive theorists propose that schemas, prototypes and scripts are cognitive structures within the mind which represent past experiences. New environmental stimuli are selectively interpreted in light of these pre-existing frameworks (see Markus and Zyjonc, 1985).

2 Fiorinal is an analgesic and sedative containing codeine, aspirin and a barbiturate. A common side-effect of this medication is constipation, which may have worsened this lady's already constipated state.

3 Synthroid is a synthetic thyroid preparation that is chemically identical to thyroxine. Many physicians prefer

After being treated for manic-depression for about a year, one woman's psychiatrist moved away and referred her to another. The new psychiatrist suspected hypothyroidism. Her Lithium[4] was discontinued but for some time her thyroid test results were inconclusive (sometimes positive, sometimes not) and it was five years before she began to take Synthroid.

Sometimes the quest for a practitioner who shares her "definition of the situation" takes the patient outside the allopathic medical establishment.

3. Alternative Health Care

One woman, already diagnosed and taking Synthroid was still not feeling very well. She had chest discomfort "like a bad lump in my throat", menstrual troubles and eventually underwent a hysterectomy. She lost confidence in her doctors, of which there were many, but none seemed to listen to her problems. They always treated her for complications of menopause. She gave up on conventional medicine for awhile and tells of a satisfying relationship with her

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to prescribe Synthroid because its strength remains stable over time, while natural preparations can deteriorate. Most of the women in this study were on Synthroid.

4 Lithium is the drug of choice in manic depression as it avoids the sedative effects of other antimanic agents but it can induce hypothyroidism as a side effect (Gold and Pearsall, 1983; Loosen and Tipermas, 1983). Whether thyroid symptoms always resolve following discontinuation of the drug is debatable. Wilson and Jefferson (1985) suggest they almost always do. Hall (1983) says that Lithium given to hyperthyroid patients diagnosed as manic-depressive produces a dramatic short-term effect that may erroneously confirm the doctor's diagnosis of mania.

holistic doctor:

> I got so disgusted with everything I went to see, how do you say, a sort of a quack. I really learned a lot from him.

His treatment consisted of substituting a natural thyroid preparation, Proloid, for the Synthroid, vitamins, a special diet, and taking her temperature daily.[5] He gave her several books and pamphlets to read. She described the diet as consisting mainly of cornmeal, lettuce, and lots of eggs, but no fats or milk. She followed this diet for three months and thinks her chest discomfort eased for a time. When it returned he referred her to an allergist. Her reaction to this new practitioner follows:

> ...he just saw me once. I walked out. I couldn't see any sense to his curing. Because he put you on some machine and he puts a cord into your thumb and then he prescribes which food you're allergic. Well, there's everything! What do you eat? I was allergic to everything. [I asked her to describe the machine.] Well, it's like one of your stereo speakers, and it's supposed to be computerized and it's got some sort of a cord out of it and he puts it up to your thumb. I think it's, yeah, he doesn't attach anything, he just puts kind of a pencil, but it's attached to the machine. And all he does is beep with this machine and it's got all kinds of figures on it and then he makes you out a list, you know, all the food written down and

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5 In the Barnes Basal Temperature Test the patient takes her axillary temperature for ten minutes immediately after awakening but while still lying in bed. A temperature below 97.8°F for two consecutive days indicates an under-functioning thyroid gland. Women should not be menstruating at the time of the test.

Before becoming a medical doctor, Broda O. Barnes earned a PhD in physiology studying the thyroid gland. With fifty years of medical practise embracing holistic health principals and having published books on the thyroid as well as several articles in reputable medical journals, he estimates the prevalence of undetected hypothyroidism in the American population at 40% (Barnes and Galton, 1976; Langer and Scheer, 1984).

> he puts down which food you're not supposed to eat. But he never told me what I'm supposed to eat or anything. He just gave me this sheet. I took a look. Well there isn't anything I could eat. And I didn't bother. I just threw it in the garbage and I never went back there, but I didn't go back to this other guy. This is one place where he disappointed me because I thought I was learning so much about my body...That just threw me off and I never went back.

Returning to a regular doctor in her home town, she was tested later for allergies and none were discovered. She has, however, remained on the Proloid.

This story reveals much about what has motivated the "virtual explosion of interest in alternative healing methods and systems" (Holden, 1978). Whether this heightened interest results in increased use of alternative practitioners or a change in the type of patients who consult alternative physicians is unclear. Although alternative health care has traditionally attracted the less affluent and poorly educated (Cockerham, 1986), several studies of alternative healing have been located in relatively affluent areas (Avina and Schneiderman, 1978; McGuire, 1987a, 1989) and an Australian study found no difference in social class between those who prefer conventional and alternative practitioners (Parker and Tupling, 1977). The visibility of alternative healing may develop as the consumer movement in health care increases (Taylor, 1984). Educated people are more likely to question medical decisions, express dissatisfaction and perhaps opt out of conventional care. They also influence the media. In contrast, universal health insurance allows the less-

affluent and poorly educated better access to orthodox medicine.

Historically, medical care has always been based on holistic health principals. As medicine became more scientific, the emphasis changed from alleviating distressful feelings and experiences to curing disease, and technical expertise became more valued than a bedside manner (Taylor, 1984). To some extent this change toward a more scientific focus was responsible for inverting the ratio of prevalence between acute and chronic disease.

Yet, a doctor's concentration on the body and disease at the expense of the self can be dehumanizing for the person experiencing illness. Several factors that contribute to dehumanization in health care are listed by Leventhal (1975). They include:

1. emotional distress, hopelessness and despair;
2. the inability of patients to communicate their distress and describe their illness to others, especially when they anticipate criticism or perceive indifference in health care workers;
3. an inability to cope with their situation;
4. uncertainty;
5. and the separation of the psychological and physical self.

Many of these factors are inherent in the nature of the hypothyroid condition and all of these factors will apply when hypothyroidism is interpreted as simply a deficiency of thyroid hormone that can be completely replaced with a daily pill.

The lady above felt dehumanized by doctors who appeared to discount her experience but found a caring relationship

with her holistic practitioner. Then, once again disenchanted by the "allergist's" complete objectification, she returned to conventional doctors.

In a culture dominated by the expansion of technology, many people who turn to alternative forms of healing, either religion-based or not, have had an unsatisfactory encounter with Western medicine. Most of these suffer from chronic illnesses (Avina and Schneiderman, 1978; Parker and Tupling, 1977). They require healing of their suffering and this "is not necessarily the same as being cured" (McGuire, 1989:58). Where the majority of illness, i.e. chronic illness, cannot be cured and where a considerable proportion of illness has no detectable biophysiological antecedent, mainstream medicine should refocus away from a narrow view of the body's pathology and towards the illness experience of the whole person. Cousins (1979) suggests that this change in orientation is already occurring.

Two women in the study were diagnosed by alternative practitioners who used an interesting technique, reflexology. These practitioners, "advocates of the Ingham technique believe that there is a direct reflex action between the nerve endings in the feet and the various organs of the body. Diagnosis is achieved by 'reading' the appropriate area if the foot" (Taylor, 1984:195).

One of these participants described her practitioner as holistic. Holism focuses on the whole person, mind and body, rather than just a disease. The patient is seen as

having the power to become and remain well by maintaining a healthy lifestyle. The healer acts as a teacher and facilitator, promoting wellness (Holden, 1978). The healer considers all factors that influence illness: work, nutrition, family, personality, emotions and environment (Cousins, 1979). This woman was referred to the holistic reflexologist by co-workers (none of whom had a thyroid problem) after she had already been diagnosed with hypothyroidism:

> She assessed your body by your feet. I don't know; what do you call that? Reflexology?... And I decided that I wasn't going to tell her that I had thyroid problems, but she told me I did. And she told me a lot of other things that I also had. Um, scared the heck out of me.

She described the practitioner as "very professional" but, after a discussion with her husband, decided against starting treatment that would cost "three or four thousand dollars." Seeing the therapy as invalid because it was not offered by a standard doctor, her employer would not allow her time off for treatments. I asked her to describe the proposed therapy:

> It was herbal. I had to do a complete cleansing which would take about six weeks, with almost daily going in there and taking certain herbs and drinks and this, as well as massage, as well as a total diet change and total, um, get me to a point of cleansing. She said, "I was in such an extreme state, it would take minimum six weeks. So that was fairly expensive for all these herbal concoctions. And then after that I would have to continue going back for, she figured, two years before I'd be at a state where I could maintain a healthy, you know. She said that she felt that there was a fair amount of damage and didn't know how reversed it could be.

The second lady described having had a lot of back problems, two breast biopsies, ear surgery and some abnormal blood tests over a two year period. When her mother suggested that she see the reflexologist she was skeptical:

> And so I thought, well, I'll just go see. He just does everything, though, with your feet and everything, and he was really quite amazing 'cause he told me where all my aches and pains were, just with my feet. And he told me, but I thought, "Ah, maybe this is hocus pocus."

She went on to tell that:

> He costs an arm and a leg. Something like fifty dollars just for a visit. I think it was. And he told me there was something wrong with my thyroid...I didn't know. It was before I had it out...but then he wanted such a phenomenal amount of money after to try to heal this. And, of course, at the time I didn't see that there was anything wrong with my thyroid. I mean, I had no symptoms yet.

The examples above illustrate how the political structure can control the availability of health care options. Canada's universal health care insurance plans serve to funnel the majority of health care users into the politically approved allopathic medical care system. Certain theorists contend that this official approval resulted from the political power of the profession of medicine (Larson, 1977). In any event the individual's prerogative to choose the type of health care she might prefer is restricted.

Apart from the powerful medical lobby, government health care schemes are unlikely to fund homeopaths and other holistic practitioners. Time is money and practitioners of alternative medicine see fewer patients per

day for a longer period of time each (Kleinman, 1978). Their diagnostic skill is based on long interviews and cannot be delegated to less expensive laboratory technicians. For this reason Coulter states that "allopathy will never be superseded by homeopathy...Homeopathy does not favor the mass production of medical services but preserves the intimate bond between physician and patient which was the hallmark of all medicine in an earlier age" (Coulter, 1984:72).

Financial considerations (as well as the holistic doctor's lack of a guaranteed cure) prevented at least one of these women from trying an alternate form of treatment. None of the study's subjects continued with an alternative practitioner long enough to fairly assess the results of their treatment.

4. Triggers to Medical Consultation

If the subjective symptoms of hypothyroidism are so easily discounted, denied and attributed to situational factors by both the sufferer and her social network, what is it that prompts the eventual visit to the doctor's office? When symptoms are not particularly salient, individual traits may affect professional help-seeking. Different people have different tolerance thresholds. Antonovsky's (1985, 1987) concept of a "sense of coherence" may help to explain this. Whether a person has an internal or external locus of control will also affect help-seeking behavior and

illness management (Seeman and Seeman, 1983). A person's culture, socialization and level of knowledge about illness can influence an individual's endurance of deviancy and her propensity to seek care (Mechanic, 1978a). A person who has developed a frame of reference for consulting doctors, and/or has seen a particular physician before, will be more likely to seek one out again when faced with bodily changes than will someone whose personal frame of reference entails independent self-treatment. Therefore a variety of personal factors will influence help-seeking behavior.

The perception of symptoms alone does not necessarily prompt a person to make an appointment with her doctor. Zola (1973) observed that visiting the doctor was not directly related to symptomatology. Neither the presence of symptoms, their seriousness, obviousness, nor the degree of discomfort they caused was sufficient to cause professional help-seeking. Instead, he identified five events that, in the presence of perceived symptoms, will "trigger" a trip to the doctor.

We have seen how people can accommodate to their symptoms, and carry on socially, personally and physically in spite of them. Zola found that when faced with an interpersonal crisis this accommodation breaks down, symptoms are noticed more and, in fact, may then be used as a cry for help and as an escape from an intolerable situation. Symptoms that interfere with personal and social relationships can be a second trigger to visiting the

doctor. The individual is relieved of the responsibility of making the decision to seek care when someone else suggests she do so. Zola called this trigger sanctioning. Symptoms that are seen to interfere with a person's work or pose a threat are another trigger. A final factor is the length of time during which symptoms are present. When symptoms persist after the individual believes she should be getting better or recur after she is better, they may initiate help-seeking.

Zola's conceptualization helps to explain professional consultation for people who may have discounted their symptoms of hypothyroidism. I identified several instances in this study. The primary triggers encountered were sanctioning and the interference of symptoms with work or physical functioning. Because most women saw the physician more than once, several triggers could be identified for some of them. The list of triggers found in this study is probably incomplete, relying as it does on remembered events, but examples illustrate the variety of factors that may help to terminate some symptom misattribution.

The following example shows the effect of an interpersonal crisis:

> He was drinking and, unusual for me, I, to some extent fought back about it. I started to cry and I couldn't stop. And I said I was leaving. He said, "Where are you going? I said, "I'm going to the (name of) Hospital and I'm going to admit myself." Which I did.

Other types of crises, not just interpersonal ones, may also highlight a person's illness. Short term memory loss created this situation for another woman:

> Like I'd go to the city and I couldn't remember where I'd parked my car. It's kind of scary so I'd get my husband to go with me. And, I'd be so tired always and I would be dragging. He kept saying, "Well, what's the matter with you?"...Till this one day I just couldn't find my car when I went to the city. I got so panicky. So from there on I went straight to see this doctor at [town]. And I just told her, I said, "There's got to be something wrong."

The above examples illustrate how the crisis may arise either from circumstances external to the ill person or, at least partially, as a result of her symptoms. The following quotation portrays a crisis arising primarily, I believe, from the symptoms this woman was enduring.

> And one morning I woke up and, like I say, because of my depressions and everything I was going through, I saw a ball out in the front yard that I'd just bought for the kids. And it just sent me off. I got angry and I hit my little girl. And I knew at that point that something like I felt like I was a volcano and I was just going to blow any minute. And I couldn't control it. And I just shoved them out the door to school and the school charged me with assault.

For this woman, this episode eventually concluded with recognition of her complaints as legitimate and indicating more that just needing a holiday as she had been told in the past. She was given psychiatric medications and six months medical leave from work. Unfortunately, she was also worried about losing her children, and embarrassed by the investigation by police and social services workers and by having to go to court. She was eventually acquitted and allowed to keep her children. After returning to work she

fought recurring depressive bouts, repeated sore throats and "colds" for several months before Hashimoto's thyroiditis was recognized and a thyroidectomy was done. The interview took place nine months after her surgery and she still was not well regulated on Synthroid.

While the subjects gave many examples of symptoms interfering in their social and personal lives, they appeared from their stories to accommodate to them quite well. Whether this reflects reality at the time or whether it is because their memories of the events contain an element of self-serving bias (Miller and Ross, 1975, cited in Baron and Byrne, 1984) I don't know. Admitting to deficiencies in social and personal relationships could be threatening to their self esteem or the impression they may have wished to make on the interviewer.

Interference with work was a frequent trigger for this group. A mature student was too tired to study. A mother was unable to complete her housework and impatient with her children. A post-secondary teacher says she never missed work before she was diagnosed but:

> I was getting to the point where I couldn't problem-solve. I couldn't control my emotions. I was very depressed. I couldn't do my job properly.

I was unable to identify any trigger operating in one particular case. This woman attributes her diagnosis to the fortuitous circumstance of deciding that a person of her age should see a gynecologist. She observed that he was

observant and astute in making a diagnosis not made by her long-time general practitioner.

The goal of Cell II is to achieve expert validation of her illness in the form of a diagnosis. The main obstacle to reaching this goal arises from the nature of the disease. Hypothyroidism is difficult to describe and legitimate to others and various barriers stand in the way of validating her experience.

B. Barriers Against Expert Validation

Several barriers appear to obstruct the achievement of expert validation or diagnosis of her illness.

1. Denial and Discounting by Others

I have already pointed out how an individual tends to discount her symptoms, especially at the beginning of an illness. A similar mechanism appears to operate when other people observe changes in her behavior or when she tries to describe her concerns to them.

a. The Lay Referral System. Initially a person's social network may also react by normalizing her experiences or attributing them to external causes. Because the sufferer's perceptions are subjective, others are unable to evaluate them objectively. When there are alternative explanations available, then illness as a possible cause of behavior change will be discounted .

The woman who taught in a post-secondary institution told of co-workers discounting her illness:

> I don't think they suspected hypothyroidism. I don't know if they suspected anything other than that maybe I was, they kept saying that I was burning out. "You're burning out. You're not problem-solving. You're not working efficiently."

In an effort to explain their perceptions, she adds:

> But, perhaps, that situation was understandable because of the stress and pressure that (type of) instructors in (location) are under...the work load is very heavy.

A related, but different type of denial of illness in others was reported by several participants in the study. In these cases other people may have noticed changes in the sufferer but neglected to bring it to her attention until after she was diagnosed:

> Most people assumed I was getting fat, 'cause I was getting middle-aged. I got a lot of comments when I started to lose weight.
>
> People look at you after you have surgery, then they say, "Yeah, we really noticed that you looked terrible...Nobody would help me. Nobody said it then. You know? And you kind of sit there, well, if they notice and everybody else notices, how come nobody could help me? Like, why do you have to go through all that before somebody can say to you, "Yeah, there's something wrong with you?"

The second woman later asked a friend why she hadn't commented on her pre-diagnosis behavior:

> And she says, "Would've you listened to me or would've you said to me, well, get out of my house!"...And I don't know, you know? It's hard to say.

I suspect there are three reasons for a friend's hesitancy to draw attention to another person's symptoms. The observer may need confirmation that her suspicions are

correct before voicing them, he or she may be conforming to a social norm of politeness, and, especially where the affiliation to the sufferer is close, he or she may fear rejection as a reaction to what might be construed as criticism.

b. The Doctor. Physicians and other experts can be as susceptible to these discounting responses as anyone else. Going to see the doctor does not always result in validation of her experience in the form of a diagnosis and treatment. Participants in the study gave many examples of physicians not recognizing their illness although Freidson (1970, cited in Cockerham, 1986) asserted that doctors are biased toward finding illness in their patients.

The woman who was admitted to the psychiatric ward after fighting with her alcoholic husband recalls how hospital employees saw the obvious immediately precipitating cause of her admission and weren't expecting to find anything else:

> They tested everything in the hospital. They tested my lungs because of my smoking and they said my lungs weren't in good shape which is natural. If you smoke they tell you that regardless and (even if) you're in good shape. Everything I thought was checked but I don't believe they checked my thyroid. No, they didn't put me on anti-depressants or anything like that. They analyzed me and said I was okay as far as they were concerned, but what I should do was something about my life.

Another who had originally attributed her symptoms to being tired because of looking after her young children eventually consulted the doctor when her symptoms persisted.

She remembers her doctors analyzing her situation in the same way.

> When I'd see the doctor they would always try to say, "Well, you're a Mom at home and its the kids and that. But it wasn't that because I knew inside that I was made of more stuff, that...like, looking after kids was something that I really wanted to do. I wanted to be home to teach them and all that and I didn't think I would react that way. And that it would be such a frustration. And the respiratory infections, they said, "Well, you're not getting enough rest. You're not getting enough sleep and looking after kids. And I don't think it was that. I haven't had one now since January.

She had begun taking Synthroid in December. The interview took place the following November.

2. Impression Management

At the same time as the illness sufferer is trying to obtain validation for her experience by employing social comparison processes, she may also be masking her symptoms as a way of preserving her own self-esteem. Goffman's (1959) thorough analysis of social interaction likened social interaction to the theater and individuals to performers. People manage their behavior in formal and public situations (front regions) so as to impress others. When they retreat to the comfort of familiar and informal settings and to the company of familiar and trusted people (backstage) they relax their guard. Mechanic (1978) also observed that people behave differently at work than at home.

Home was their backstage area for these women. They told of sleeping ten to twelve hours at night in order to

work the next day, of the laundry piling up, and of being too tired to cook or even eat what someone else prepared. A proud housewife told of spending the summer sun-tanning for the first time in her life, instead of doing her housework and gardening. Even at home some women tried to keep up a "front" of normalcy. When I asked one if her husband had also attributed her tiredness to family stress as she had, or been concerned about her health, the reply was:

> I don't think he was concerned about my health particularly, especially when I'd come home and say, "I'm fine."

Several times I was told how these women were able to function in places where it mattered but collapsed onto the couch when they got home. I asked if co-workers had ever commented on their changed behavior or suspected hypothyroidism. Apart from the examples I have already cited under the lay referral system some replies were:

> No. Never. 'Cause I really forced myself. I really kept, I worked. I'm a hard worker. And I wasn't going to let that, you know.

Another said:

> I'm always running at work and stuff. So I don't really fit the image.

Despite their attempts to present as "normal" several admitted their work was affected. Some examples follow:

> And your thoughts aren't clear. You're not able to articulate as you would be and to be able to think quickly as you would be if you were at your normal level.

> My memory has never been good. It's a wonder I'm holding my job.

When unable to keep up at work a couple of subjects said they would book off sick. One who was being treated for depression requested a reduced work load. She and one other subject were given some medical leave from work. Two women did quit their jobs.

Not one, however, was fired from her job. Not one admitted to a supervisor's criticism that she needed to improve her performance. This may only partially be a result of the subject's impression management. Another explanation is that people often view another's behavior in terms of their own expectations of what it should be and ignore behavior that is inappropriate. Pirie observes that "illness states which incorporate an affective component" (1988:643) are likely to ignored in the workplace.

Even when they go to see the doctor, people tend to "put their best foot forward". The woman whose ear doctor eventually diagnosed her condition recounted:

> He just looked at me and said, "God! You look dreadful." And I, sort of, "Well, thanks a lot! Here I put a little make-up on this morning and tried to look nice for you and everything"...I mean, you don't want to go to a doctor looking terrible or anything, you know.

Although impression management allows some hypothyroid sufferers to maintain their self-esteem and fulfill their social roles, it can also contribute to the stress and strain of being ill and to the length of time before their

illness is recognized. As one study participant said:

> ...so you kind of go along with it and hide your emotions. You try to hide your emotions, put on a good front, but it's still inside, you know?

3. Labelling and Blaming the Victim

In much the same way as individuals suit their behavior to the impression they wish to create, one person responds to the impression she holds of another person. Positive or negative labelling of her health status by others will influence their behavior towards her. When signs of illness are ambiguous then a person's health identity (label) results from negotiation between that person and those in his or her social network (Twaddle and Hessler, 1987). In consequence, if the afflicted person is having difficulty defining the meaning of her illness, she will have some problems influencing this negotiation process.

a. By the Lay Referral System. This research project uncovered many instances in which the subject was aware of a negative attitude from friends and acquaintances. When negative labels are made in response to a person's symptoms of illness, the effect is to blame the victim of the illness for deficiencies over which she has little control. As one subject said:

> The thing is when you haven't any energy you're looked upon as being slow and lazy. It's only natural, okay?

One of the three sisters spoke of her uncle:

> ...and he was just the sweetest guy going, but you know it was hard for him. In those days there was no

> treatment,[6] you know, and he was looked upon as being slow and everything.

Others said:

> ...other people don't understand. They just think that you're miserable.
>
> And he [her husband] says maybe, you know, maybe I'm bringing this on myself.

In telling of her memory loss one lady laughed and said of her co-workers, "I think they just think I'm this spinney broad."

The following comment shows a lot of insight into the problem:

> ...the changes that people see, sometimes they think it's a, like your personality is changing. I know my mother-in-law said that I wasn't the same person...But they're not looking at you as if it's a medical problem.

When the negative label is psychiatric, and for many of these women it was, the effect can be particularly troublesome. When that psychiatric label carries the authority of a physician's diagnosis, then even her normal behavior can be overlooked or misconstrued as manifesting mental illness (Rosenhan, 1973). In this way pejorative psychiatric labels are self-sustaining. They are also self-fulfilling when the labelled patient eventually comes to believe the label. This is evident from the woman who was diagnosed as manic-depressive:

> ...to go through a certain period of my life, in my twenties, believing that I had an incredibly devastating mental health problem, manic depression and, and label myself and therefore believe that I

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6 In actual fact desiccated thyroid hormone was first used to treat hypothyroidism around 1900 (Hudacin, 1985).

> couldn't do a number of things and I just gave up on a lot of goals because I was this defective manic-depressive.[7]

b. By the Doctor. Once the thyroid sufferer went to see a doctor, these same processes often took place. The following woman was labelled depressed and obese but no attempt was made to find out the reason for either.

> This depression all the time. I was going to doctors, numerous doctors saying, "Help me, like this isn't me. There, there's something wrong." And they would say, "Oh, you're just going through a depression. You need a holiday"... I kept going to doctors. They were putting me on uppers and all kinds of things, you know? One doctor said, "What are you depressed about?" I had started to gain weight. I said, "Well, look at me; I'm gaining weight and everything." He put me on diet pills. They just made me really hyper.

Later in the interview she said:

> I would cry in their office bitterly and, and you know try everything. "There's nothing wrong with you." Nobody would even take a blood test. Nothing. They just told me I was depressed.

With menstrual bleeding lasting through all except one week of each month, the obvious label for one lady was menopause:

> But the worst part of all is they [always] treat you for menopause. That is, I'd come home and I'd tell my husband, "I wonder if that's all they learn in University is menopause for women?" That was, no soon I tell them my age, it's I'm in the menopause stage.

Having labelled this woman, the doctor effectively blocked out any perception of additional information about her

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7 Determining whether this woman's manic depression or her hypothyroidism came first is difficult. Hypothyroidism can cause symptoms consistent with manic depression. Lithium, with which she was treated, can cause hypothyroidism. She believes that she was hypothyroid first, a belief that is supported by her freedom from manic depression since being on Synthroid.

symptoms and stopped looking for any other explanation for her menorrhagia.

After several visits to her doctor and having been told to slow down at work, eat less and exercise more, one interviewee's husband became very worried. He visited the doctors himself:

> ...a couple of the ones that I had gone to before, you know. "What's the matter with my wife? Something is wrong with her. She's not normally like this." He'd say, "She isn't. I know. I live with her." "Oh well," [said the doctor], "she's sneaking buns at work." And he [her husband] was getting quite angry as well.

The doctor makes a diagnosis by identifying a particular constellation of signs and symptoms commonly experienced by patients who have a particular disease. His ultimate goal is to cure his patient's disease by recommending treatment that is appropriate to a particular diagnosis. That goal is thwarted when all patients suffering from a particular disease are not "sick in precisely the same way" (Coulter, 1984) and when the signs and symptoms overlap among several diagnoses.

By referring again to the symptoms experienced by the participants in this study (Tables 4 and 5) it becomes immediately apparent that the hypothyroid symptoms fail to conform to any easily recognizable pattern. Hypothyroidism has been called "a treacherous masquerader" (Acute Care Medicine, 1984) because an individual patient's list of symptoms may mimic those of another disease. Someone with

hypothyroidism may concurrently suffer from other diseases.[8] The patient with autoimmune thyroid disease is prone to other autoimmune conditions.[9] All these factors contribute to a confusing illness picture facing the diagnosing clinician.

Several analysts of the medical profession have criticized doctors for their reductionism in narrowly focussing on the body or even upon a particular organ. The effect is to depersonalize and dehumanize the patient (Leventhal, 1975; Todd, 1989). Physicians may prefer to base a scientific diagnosis on objective pathological signs that can be assessed by laboratory testing and physically examining the patient. Yet clinical judgement is also based on verbally probing the patient for her subjectively experienced symptoms during both this episode of illness and her past medical history.

When the sufferer is faced with ambiguous sensations she turns to external sources for confirmation of their meaning. Similarly, I suggest that the competent physician

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8 Eight subjects volunteered information about other diseases they have, or had before diagnosis that would confuse the picture and could influence or be influenced by her hypothyroidism. These include iron deficiency anaemia, an elevated sedimentation rate (usually indicating an infection somewhere in the body), hypertension with a history of rheumatic fever, hypertension with a history of kidney disease, juvenile onset diabetes, severe jaw problems requiring reconstructive surgery, psychiatric problems, back problems, ear surgery, breast biopsies, endometriosis, a spastic colon, an intestinal parasite following overseas travel, and allergies.

9 For a list of autoimmune illnesses linked to hypothyroidism refer to page 11.

when presented with ambiguous symptoms will begin to look beyond symptom classification to other characteristics of his patient.

In so doing, however, the physician's own cultural background, his childhood and professional socialization and his past experience with this patient, or patients in general, come into play. Unless faced with strong evidence to the contrary, preconceived schemas will influence his assessment. People can be stereotyped according to many characteristics and women with hypothyroidism are liable to be judged by at least three. Because of the nature of her disease and her associated illness experience, she is likely to present to the doctor in a manner evoking the following stereotypes: the "typical" female, the hypochondriac and the difficult patient.

i. The "Typical" Female. Feminist theorists highlight the economically and politically disadvantaged position of women in society. Little girls who are socialized to be passive and dependent are doomed by their second-rate education and public expectations to occupational and social prejudice. The feelings of dissatisfaction, incompetence and frustration experienced by the woman who is "just a housewife" and the stressful role conflict of the working mother lead to increased morbidity rates for women (Roberts, 1981; Trypuc, 1988). An unfortunate consequence of raising the public's social consciousness regarding sexual inequality may be that

physicians (especially those, ironically, who are most sympathetic to their female patients) may be even more prone to dismiss a woman's illness as resulting from her disadvantaged position and, therefore, short-circuit the need for a thorough clinical investigation.

Research outlines how the doctor/patient relationship mirrors the patriarchal and hierarchical arrangement of our society (Todd, 1989). In the majority of consultations the patient is a woman and the physician is male (Barrett and Roberts, 1978; Roberts, 1981; Trypuc, 1988). Physicians naturally identify more closely with male problems than female ones (Barrett and Roberts, 1978). In one study doctors were asked to rate the patient immediately after each appointment. Those whom they favored were male, with specific organic and physical symtomatology that was easy to diagnose and treat, and which had a good prognosis. Conversely, patients who gave them the most trouble were females with chronic illnesses who were hard to diagnose and treat because of their vague symptoms and social problems. (Stimson, 1976; cited in Roberts, 1985).

A Canadian study concluded that doctors were more uncomfortable, anxious and frustrated by female patients than males (Dungal, 1978). In separate studies doctors describe women patients as typically worried about nothing, hysterical, neurotic (Barrett and Roberts, 1978) and prone to trivial complaints (Wallen et al, 1979). Wallen's research also showed that women were more likely than men to

be diagnosed physically well, and in the absence of a defined organic disease to be treated with tranquillizers or referred to a psychiatrist. This latter point has been also been made by McGuire (1987b).

ii. The Hypochondriac. "Many investigators of hypochondrical patients note that reported symptoms tend to be diffuse and may change from one occasion to another. Such patients often report numerous complaints referring to a variety of organ systems, or they report nonlocalized symptoms: insomnia, itching, dizziness, weakness, lack of energy, pain all over, nausea and the like" (Mechanic, 1972:1134). In addition their symptoms are non-specific ones that occur widely when people are "well" and often are related to stress. Such a patient presents to the doctor time and again. Various tentative diagnoses may be made and various treatments tried without success. Sooner or later the patient's problems are labelled psychosomatic, a term that is sometimes interpreted as implying a "willful patient who is needlessly sick " (Todd, 1989). Continuing problems breed frustration for the doctor (Dungal, 1978) as well as the patients.

The above description could just as easily apply to many hypothyroid patients. Physicians sometimes label hypothyroid patients as hypochondriacs (Barnes and Galton, 1976; Langer and Scheer, 1984) and some of the subjects in this study were so labelled. Even if the doctor didn't actually say so, the patient often believed he had that

opinion. The effect on her was to increase her uncertainty, reinforce her feelings of inadequacy and foster repeated visits and doctor-shopping.

> ...went back to the doctor again. I said, "Something's wrong...There's just something wrong and you guys aren't, you're not looking at me." And [the doctor's response was], "Oh no." You know, they almost made me feel like I was a hypochondriac. I'm trying to come up with something, an excuse for the way I feel. So okay, back you go again.

Later in the interview the same woman said:

> And they look at you like, "Oh, we've got another one in the office." You know? And they sort of reject you.

A second woman told a similar story:

> I couldn't get anyone in the medical profession to believe that anything was wrong. I would go to my family doctor and say, "Why am I so tired? Why am I gaining weight when I'm not eating enough to gain all this weight?" And I would get excuses like, "Well, you're working too hard. Um, you're eating too much. Eat less lady. Exercise more." And almost like, "Well why are you bringing these complaints to me. You're a hypochondriac who's eating too much." And this went on for at least four years, or maybe it was five...before I finally went to four different GPs in a period of about three months [until one discovered that I was hypothyroid].

iii. The Difficult Patient. Patients who are seen as "difficult" are both hard to get along with and hard to diagnose. Obviously physicians do not approve of the hypochondriac. Likewise, the "typical" female patient is viewed by the doctor as presenting more problems than the male. The "difficult" patient as perceived by the doctor may be either female, hypochondrical or both.

Physicians describe patients they like as grateful, cooperative, able to cope, happy, settled and confident.

Contrast that description with patients who are demanding, ungrateful, critical, unable to cope, unhappy, unsettled and lacking common-sense. These are behaviors doctors do not like (Stimson, 1976, cited in Roberts, 1985). Physicians, like anyone else, respond best when positively reinforced.

Success in the medical model equates with "cure" and one study found therapists were less confident about their success when patients were homely, old, unattractive and "dumb" (Johnson and Kurtz, 1990). Patients with unrecognized hypothyroidism, with their swollen features, droopy eyelids, premature aging, memory loss and trouble concentrating come to fit this description.

Doctors also like patients who present with new problems more than continuing ones (Dungal, 1978) and with problems deemed significant not trivial. Most of a physician's work is repetitive, however, and deals with minor problems (Stimson and Webb, 1975). A quotation from a physician who became a patient sums up the prevailing attitude toward difficult patients:

> When the necessary organic and biochemical indicators did not appear, I worried that I would be classified as a "crock",[10] and I felt outraged indignation and defensiveness. At last it was confirmed that I had viral pericarditis. My reaction was vast relief. To survive with minimal dehumanization in a teaching hospital there is nothing better than a moderately serious, reasonably benign, incontrovertibly organic

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10 " 'Crock' is a derogatory term used by some physicians to describe patients who do not present clear cut symptoms of an organic disease, who are suspected of having only neurotic anxiety--and who do not gratify the physician" (Geiger, 1975:13).

illness with a good prognosis and just enough rarity to interest the physician" (Geiger, 1975:13).

The nature of the hypothyroid sufferers illness appears to conspire against her and encourage negative labelling by both her social contacts and by the physicians she consults.

4. Structure of the Doctor/Patient Relationship

a. Dynamics of the Doctor/Patient Encounter.

Encounters between physicians and their patients exemplify a negotiation process. When the goal of a mutually acceptable diagnosis and treatment is reached each party's reward is validation. The patient's experience is recognized and given a "stamp of approval". Likewise the physician's proficiency is acknowledged. However, the achievement of a shared meaning for her illness, and hence a diagnosis approved by both, is a result of their interaction and maneuvering, not just the direct application of his diagnostic skills to the facts she presents. Negotiation can place the hypothyroid sufferer at a disadvantage.

Analysts of the encounter between physicians and patients describe a situation of inherent conflict (Freidson, 1961; Stimson and Webb, 1975) predicated on differing perspectives: the doctor's is biomedical and the patient's more contextual. Todd (1989) examined transcripts of physicians interviewing patients and found that the doctor's question and answer style dominated the conversation. At the same time the patient's story-telling manner gets discounted as too subjective and as "social commentaries deemed inappropriate to the issues at hand"

(Todd, 1989:94). The result, Todd says, is that patient's real concerns get overlooked. A criticism of Todd's methodology is that studying communication between doctors and patients allows one to propose a theory of communication only, but not a theory of interpersonal relations (Stimson and Webb, 1975).

Some suggest that women patients need to be more assertive and factual. Birenbaum (1981) observes that when patients fail to clearly express their symptoms, the physician may neglect to perform a complete examination and some important diagnostic procedures. Others recognize the inequality of power in this encounter and suggest the physician should yield to her. Roberts (1985) advocates patients keeping, and presumably doctors reading, health diaries for chronic illnesses. McCurdy (1990) admonishes that only by respecting the patient's automony and taking the patient's story seriously will health practitioners make fully informed and fully ethical decisions.

b. The Time Factor. Listening to patient's stories involves time.

> Time is the one thing that patients need most from their doctors--time to be heard, time to have things explained, time to be reassured, time to be introduced by the doctor personally to specialists or other attendants whose very existence seems to reflect something new and threatening. Yet the one thing that too many doctors find most difficult to command or manage is time. Indeed, some doctors tend to favor the new technology precisely because they don't have time enough to allow the diagnosis to emerge from comprehensive direct personal examination, and from extended give-and-take with the patient (Cousins, 1979).

Researchers agree that when physicians allow more time and undivided attention for each patient then more humane and better health care results (Geiger, 1975; Howard, 1975; Janis, 1975; Kennedy, 1975; Kleinman, 1978; Mechanic, 1975). Howard (1975) cautions that if we propose restructuring the doctor/patient encounter we need to discover the mechanism for how time influences good care. Is time a predictor, an outcome or an intervening variable? Ironically, a further warning is that by enforcing longer consultations upon some patients who have a busy competitive lifestyle, the physician may dehumanize *them* and reinforce their reluctance to take time off to see a doctor (Levine, 1975).

Canada's health care insurance plan pays doctors on a piece-work basis for procedures completed and fails to reward practitioners for taking the time necessary to listen to their patient's stories. Physicians often respond by cutting the consultation time in order to "service" more patients (Advisory Committee on the Utilization of Medical Services, 1989). No matter whether the system or the doctor is at fault, the dilemma remains. By increasing the time given to each patient the physician will reduce his income but also may reduce the access of some patients who may need his expertise (Mechanic, 1975). To provide a fully humanized health care system in which physicians spend more time listening to their patients may entail increasing the number of physicians and, hence, the cost of health care delivery.

c. The Cost Factor. One of the ironic results of scientific medicine's success in curing acute and infectious diseases and thereby extending life expectancy has been to increase the demand for health care. Chronic illnesses increase with age and chronic illnesses require on-going care. The crude fact is that quick deaths cost less than prolonged convalescence and disability. Faced with the escalating costs of a universal health care program, the provincial governments in Canada attempt to improve their efficiency by rationing those services thought to be less important. A cost-effective service does not always translate into fully effective care. One example, I believe, can be found in the recent guidelines proposed for thyroid testing.

5. Laboratory Tests for Thyroid Hormone Levels

The Advisory Committee on the Utilization of Medical Services reported to the Government of Alberta in October, 1989. Among its recommendations was that "a full series of thyroid function studies should not be paid for unless it had been preceded by the appropriate screening test" (Section 13.2.6).[11] The justification given is:

> The practise of ordering a complete thyroid profile (three separate tests: T4, T3U and TSH) as a screening battery is very expensive (Section 3.2.15.i)

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11 One large U. S. study advocating cost-effectiveness recommends the progressive testing profile (Nolen et al., 1985). This is the research upon which the Advisory Committee based its report (Young, 1988; College of Physicians and Surgeons of Alberta, 1989).

> Physicians in Alberta can significantly reduce the amount of money spent on thyroid function testing to detect unsuspected thyroid disease if they adapt a progressive profile. One test (T4) will effectively screen 90% of patients who will require no further testing. The other tests are for the 10% of patients whose results were not normal. Even with the costs of the extra visits for that 10%, the potential savings to the province would be approximately 50% of the cost of current practise (Section 3.2.15.iii).

As a result, the Report from Council of the College of Physicians and Surgeons of Alberta (1989:32) recommends that physicians employ the progressive thyroid profile and order only the T4 as the initial screening test.

A review of the appropriate literature suggests an inherent flaw in this justification that is caused by neglecting to differentiate between hypothyroid and hyperthyroid conditions. Where an increase in the T4 level (thyroxine hormone) is indicative of hyperthyroid disease, the T4 test fails to detect early hypothyroidism (Canadian Task Force on Periodic Health Examination, 1990; Gold et al., 1981). Instead, TSH is more sensitive to early pathology and favored (Table 7) for discovering thyroid failure (Bahemuka and Hodkinson, 1975; Bayliss, 1982, Canadian Task Force on Periodic Health Examination, 1990, Evered, 1976; Gordin et al, 1974; McConahey, 1975; Sawin et al, 1975; Tibaldi and Barzel, 1985), although the TRH may be even better for autoimmune thyroiditis (Gold et al., 1981; Gordin et al, 1974). Haggarty et al. (1986) advocate TSH levels to evaluate most depressed patients, especially those with cognitive dysfunction.

TABLE SEVEN

THYROID TESTS FOR DIFFERENT GRADES OF HYPOTHYROIDISM

Table withdrawn for lack of copyright.

*source: Table 5. Bayliss, 1982:68

Measuring circulating thyroid hormones, T4 and T3, will detect overt hypothyroidism (Table 7), that would likely be clinically evident anyway. To increase its diagnostic sensitivity, one study (Nolan et al., 1985) increased the lower limit for the normal range to 55mg/L from the more usual T4 reference limit of 45 mg/L., yet the Alberta recommendation neglects to state what level of T4 should be considered abnormally low. At any rate there seems to be some variation in standards for thyroid testing. Evered (1976) states that the normal range for thyroid hormone

concentrations varies from publication to publication and from one laboratory to another. Measuring T4 *might* detect mild hypothyroidism but will definitely not differentiate the subclinical form.

There appears to be agreement that mild hypothyroidism is manifest by several uncomfortable symptoms and warrants treatment (Cooper et al., 1984; Nystrom et al., 1988; Rosenthal et al., 1987). With subclinical hypothyroidism the verdict is mixed. Gordin and Lamberg (1981) estimate that over one quarter of the symptomless patients who have an elevated TSH will develop overt hypothyroidism within four years. Two studies unequivocally advocate treatment, for those with subclinical hypothyroidism, stating that the low doses of thyroid hormone can prevent the development of overt disease (Tibaldi and Barzel, 1985) and that there is a danger of precipitating heart problems if treatment is withheld until the disease is obvious (Bahemuka and Hodkinson, 1975). Conversely, Bell et al. (1985) state there is no justification for treating autoimmune thyroiditis unless symptoms are observed and Sawin et al., (1979) are not sure.

Others suggest subclinical hypothyroidism requires treatment but qualify the recommendation. Subclinical thyroiditis requires treatment when there are microsomal antibodies (Rosenthal et al., 1987) and if there are ECG changes indicating cardiac involvement (Cooper et al.,

1984). Nystrom (et al., 1988) suggests a six month trial when the patient is tired or depressed.

The following quotation sums up the sad consequence of not treating the patient until overt hypothyroid symptoms are present:

> For the individual patient the years of subnormal functioning, "physician-shopping" for an explanation of their "malaise" and being labelled as depressive certainly carry a heavier burden on the quality of life than the actual course of the disease" (The Canadian Task Force on Periodic Health Examination, 1990:958).

Screening patients without clinical evidence of thyroid disease is controversial. Faced with the prohibitive cost of full-scale adult screening for thyroid disease, the Task Force has designated, as a priority, research to compare clinical screening without laboratory follow-up vs TSH testing . Several authors advise screening the elderly (Falkenberg et al., 1983; Rosenthal et al., 1987; Tibaldi and Barzel, 1985; Sawin, 1979; Bahemuka and Hodkinson, 1975). All of these authors propose using the TSH test. Nystrom et al. (1981) advocate screening women in their mid-fifties; Gold et al. (1981) propose screening depressed, tired and anxious patients; Bahemuka and Hodkinson (1975) advise concentrating on women with autoimmune disease, depression, apathy and failure to thrive.

Until the Task Force's research has been completed the Government of Alberta's acceptance of their Advisory Committee's recommendation would be premature. Were A.H.C.I.P. to refuse payment for further thyroid testing when the T4 appears normal, then many cases of early and

mild thyroid failure causing years of patient suffering could be missed. In the final analysis the over-reliance by physicians upon laboratory results should never replace conscientious clinical investigation, comprising a thorough physical examination and careful and empathetic consideration of the sufferer's reported symptoms.

In the absence of the TSH test, individualized interpretation of the T4 level is important. "Normal" ranges are calculated from an aggregation of people so that "the normal range of thyroid hormone concentrations in an individual are very much narrower than for the general population" (Evered, 1976:32). A low normal T4 value should alert the physician to the possibility of mild or subclinical thyroid failure and the likelihood of the patient's developing overt disease in the future (Rosenthal et al., 1987; Sawin et al., 1979). Tibaldi and Barzel (1985) highlight the importance of baseline thyroid testing before any clinical symptoms appear, in order to assess the individual's "set point". In autoimmune thyroid disease, hormone levels are know to fluctuate (Nystrom et al., 1981) so that a single test may not show any abnormality. Laboratory testing for thyroid disease is more accurate than it was years ago, but I suspect the considerations above might have led to an earlier diagnosis for some subjects in this study:

> ...my physician thought there was a medical reason for it and had numerous tests done. And, thought there was a thyroid problem, but then when he'd go to retest it, my thyroid would seem to be normal again, and then

> he'd, months or so later, we'd do another test and it would be abnormal and so, he wasn't sure.
>
> And because I have a rare type of hypothyroidism, blood tests don't indicate, the old T3, T4 does not pick it up. And the docs were looking at T3, T4. And because they were technically within normal limits they were saying, "Well, it can't be." There's no use in going further. But as soon as I went to the endocrinologist, she looked at the blood test results and she said, "Oh, you have peripheral resistance to thyroid hormone. The signs are all there. Your blood tests indicate this very clearly. But the GPs didn't pick this up, that there is a very distinct pattern, even though T3, T4 look like they're within normal limits, the proportions are way, way out. But, and you know, so they kept doing these tests and they kept saying the tests were normal...The GP that I finally went to, who just took one look and said, "This must be", I had the test results from the T3, T4 and he just looked at them and he said, "Well, these say that you're not hypothyroid but one look at you says you are." And so lab tests sometimes don't tell the whole story.

Recommending that thyroid testing be done in a stair-step fashion in which the ordering of one test is predicated on abnormal findings of the previous one delays the diagnosis and prolongs the suffering for individual patients. Repeated visits to the doctor during this process will also drive up health care costs.

> ...where I was disappointed with her [my doctor] is, instead of really working with me, she, first thing she sends me to seven or eight different tests I have to take. And these tests were going to take like six, seven months, you know, by the time it's finished with all of them. I just took a few of them then I quit. I thought, "That's not my way of getting well." She even sent me for a scan test. I had nothing against it but I had to wait something like six, seven [months] to get all that finished, 'cause you couldn't get into some of these [without a long wait]. And then I have to come to her. But then that was, I thought that was too long so I just, I never went back to her and I never finished them.

Admittedly, diagnosing thyroid disease is difficult. More definitive testing has recently been developed, so that

the diagnosis of some of the women, missed years ago when testing was less available and less accurate might, in similar cases today, be picked up. Even now the basic blood testing of hormone levels is the starting point. Patients will accept having several highly technical tests more readily when the tests and reasons for them are fully explained. One subject obviously had not been very well prepared for her thyroid scan:

> I went in there and when I drank this stuff I was nervous and that, 'cause I thought, "Oh God! I'm radioactive now." You know and I'm goin' to glow at night, you know? I drank that stuff and they did whatever their procedures that they had to do, and then that night I was at work and I was sittin' there and all of a sudden it was like my neck fell out of me. It was the weirdest feeling, like I was, I was sittin' there and all of a sudden I went, "Uhh" [catches her breath and clutches her neck] like this, and (co-worker) looked at me. He goes, "(subject's name), what's the matter?" And I says, "I can breathe." And he says, "Well, yeah. You've been breathing, like, what's wrong with you?" And I says, "No," I says. But I guess the radio-active stuff sometimes will make the swelling go down, is what I was told. I don't know. So anyhow, I thought, "Well, okay, I feel fine." And they told me that I wouldn't have my results from that for at least a week or so, but I had them the next day.

C. Outcomes of Cell II

1. Delay in Achieving Expert Validation

For hypothyroidism the pathway to the doctor's office is a complex and often lengthy process. By subtracting the sufferer's age at her first remembered symptom from her age at diagnosis (Table 8) we discover that for only three subjects was the difference one year or less. Only one of these three reported cyclic symptoms. Of the remainder the

delay ranged from five to thirty-nine years, a mean of 13 years. This is much higher than for Hudacin's (1985) survey of the Thyroid Foundation of Canada, in which the average delay from age at onset to age at diagnosis for female hypothyroid sufferers was only 1.9 years.

The difference in the two studies is probably due to a difference in definitions. "Age of first symptom" designates the very first symptom the patient attributes to hypothyroidism, whereas Hudacin probably counted age of onset as the first symptom that lead to the suspicion and diagnosis of hypothyroidism. In Table 8, "age suspected"

TABLE EIGHT

REPORTED DELAY IN DIAGNOSING HYPOTHYROIDISM (IN YEARS)

Subject	Age of First Symptom	Age Suspected	Age at Diagnosis	Delay From First Symptom To Diagnosis
01	16	16	29	13
02	35	35	43	8
03	34	35	35	1
04	13	41	52	39
05	36	37	41	5
06	16	16	29	13
07	16	25	25	9
08	29	29	29	0
09	27	27	37	10
10	58	58	58	0
11	21	53	53	32
12	20	48	48	28

was designated to mean the age at which the subject could recall first being tested for thyroid disease. For those who were unable to remember, I arbitrarily assigned the age

when she first suspected thyroid disease whether that was suggested by herself or anyone else. The difference between "first symptom" and "age at diagnosis" was particularly long for subjects: 04, 11 and 12, averaging 33 years. Three of these have Hashimoto's thyroiditis and reported having cyclic symptoms. Most of the delay occurred before hypothyroidism was ever suspected. This delay is likely due to the historical unavailability of definitive tests, but some of it may be due to long periods of remission.

Six subjects waited a long time between having thyroid disease suspected and being diagnosed. For subjects 01, 02, 04, 05, 06, and 09 the average wait was 9.8 years. Three of the six reported cyclic symptoms and two have Hashimoto's. Note that for subject 04 both delay periods were long.

For three subjects the total delay was a year or less. Two of these, subjects 03 and 10 have managed very well on their thyroid replacement. Subject 08, however, reports cyclic symptoms interfering with her functioning both pre-diagnosis and while on treatment.

Safer et al. (1979) analyzed the factors that predict delay in going to a medical clinic. He divided the total delay into three periods. Unfortunately his periods do not match the two phases I have described above. However, in Safer's study the best predictors of short delay in appraising one's own symptoms were severe pain, bleeding and not reading about one's illness. Experiencing new symptoms as opposed to old predicted a short delay between deciding

one is ill and looking for professional help. In contrast, one would expect old and less severe symptoms, and the behavior reading about illness in an effort to diagnose oneself would increase the delay.

It is no surprise then that many hypothyroid sufferers take a long time to seek professional help. From a small study one can predict only tentatively about hypothyroid patients in general, however it seems reasonable to hypothesize that vague and subjective symptoms, insidious onset, the on-off nature of cyclic symptoms and autoimmunity (Hashimoto's) would predict increased delay in achieving expert validation, i.e. a diagnosis, for sufferers of thyroid disease.

2. Transition from Cell II

In Cell II the ill person is seeking validation of her illness from others. This may be either lay-validation or expert-validation. How she reacts to other people's advice will affect her position in the typology.

a. Lay Validation. Sometimes lay people may give treatment advice which she decides to follow. If she gets better she moves down to the lower right corner of Cell I. If not she will continue help-seeking in Cell II.

b. Expert Validation. In the ideal case she receives expert validation in the form of a diagnosis and prescribed treatment. If she accepts the doctor's decision she enters Cell III and begins the treatment. If she accepts the

diagnosis but decides she doesn't require his treatment in order to get well she has two choices. She may stay in Cell II and seek other treatment advice, or she may decide she is well enough not to require treatment, which would move her to Cell IV. On the other hand she may not accept the doctor's decision in which case she stays in cell II and looks for an alternate diagnosis. Remember that if at any point the sufferer decides she is no longer ill and that she has no symptoms, she situates herself at the lower right corner because there is no longer any need to seek validation.

A diagnosis along with its prescription of treatment is a particular form of labelling seen by both physician and patient as the objective of the doctor/patient encounter. Giving a name to her illness validates her experience and restores some measure of order to her existence. In describing their immediate reaction to being diagnosed with hypothyroidism almost every subject expressed relief that her fears of going crazy or of having a more life-threatening disease were unfounded.

Only one woman was upset with the diagnosis and convinced that her doctor was mistaken. The idea of having any chronic disease can be frightening. In this case, lacking a full explanation of the disease from her physician, this woman was very fearful. She describes crying until she was reassured by a neighbor who was a nurse. Two subjects were initially fearful of cancer before

having surgery but were relieved following: one by having no malignancy, the other by her improved health. Overall, most of the sufferers of hypothyroidism entered into treatment optimistically anticipating recovery.

CHAPTER SEVEN

CELL III EVALUATING PRESCRIBED TREATMENT

With a specific diagnosis the hypothyroid sufferer enters a new phase of her illness trajectory. Strauss concentrated on this phase in his theory of chronic illness when he described the trajectory work in which people engage, in order to manage their chronic illness. At the same time as she is cooperating in the prescribed treatment, the sufferer of an illness is continually evaluating its success. The goal of Cell III is to achieve complete validation, whereby the patient and doctor are in complete agreement about the efficacy of this treatment and the degree to which it alleviates her illness.

A. Strategies for Complete Validation

The action strategies employed by the sufferer in Cell III, as described by Strauss (1975), are preventing and managing medical crises, managing the treatment regime, controlling symptoms, adjusting to her illness, normalizing her life style, dealing with social isolation, and obtaining funding.

1. Preventing and Managing Medical Crises

Strauss analyzed chronic illnesses with poor prognoses. In spite of periodic plateaus and temporary remissions, their courses were marked by illness crises: exacerbations, complications, and an overall deterioration toward eventual

death. Fortunately the prognosis for treated hypothyroidism is better -- good enough in fact that almost no one alerts these women to a potential for relapse. Once they have been given an appropriate dosage of thyroid hormone, the expectation is that their troubles are over.

Many subjects recounted at least one episode in which their symptoms returned or worsened. At the initiation of treatment many appeared to have a thyroid gland that was producing some hormones. Later, when the thyroid damage progressed, their replacement dosages became deficient. For some the remedy was relatively easy, getting the doctor to increase their medication. For others, the symptoms slowly became worse and again were discounted or attributed to other causes and there was a delay before the problem was rectified. Had the sufferers been forewarned, their own symptom monitoring might have been better and their episodes of illness shorter.

2. Managing the Treatment Regimen

Once again the person with hypothyroidism is luckier than many with other chronic diseases. The treatment regimen consists of taking a pill every day. Strauss lists the characteristics of regimens and this one appears to have positive characteristics on almost all counts. The treatment works and is easy to learn. It takes little time and effort, causes no discomfort or stigma, is invisible, and allows her to increase her social activity. The final

two features that he listed are the expense of the treatment and whether or not it causes side effects.

None of the subjects mentioned that the medication was expensive. This leads me to the conclusion that whatever the expense, it is outweighed by the efficacy of the drug. One subject did mention that for a time she was buying her medication a month at a time as the doctor ordered. Then she discovered that by buying a six month or one year supply she could avoid paying the dispensing fee every month. She was irritated that neither the doctor nor the pharmacist had informed her of this, saying "it must be really hard on some people who are on a low budget." Buying in bulk may work for the synthetic medication but the natural thyroid hormone preparations will deteriorate over time.

None of the participants in the study disputes the effectiveness of thyroid hormone replacement for hypothyroidism. Most of them are taking Synthroid (synthetic T4) although one is on Proloid (natural T4) and one on Cytomel (T3). All admit to being better now than they were before. It appears to be a safe drug, but patients should be informed about the symptoms of hyperthyroidism because if these appear her dosage will need to be reduced. Other than inducing hyperthyroid symptoms when overdosed, there are no reported side effects.

Subjects in this study, however, believe there are. One subject is convinced that since starting her medication she becomes ill whenever she drinks alcohol. Even one drop

produces palpitations, hot flushes and a severe headache. Following that interview I questioned others. The results were inconclusive. One woman said that alcohol seemed to make her more excited; another said there was no difference; and several others do not drink.

One woman believes the medication has this side effect:

> I find that I'm quite nervous and edgy which I never used to be before and I kind of attribute that, possibly, as a side effect of the medication 'cause before I was very calm and easy going. I am still easy going, but I find I just get very jittery. And that is after going on the medication, you know? So I think there are some side effects and yet they tell you there are none.

Perhaps this lady's jitters along with her heat intolerance indicate that her hormone level is quite high and on the verge of hyperthyroid manifestations. At the same time she continues to have difficulties with fatigue and lack of energy. Tiredness is also a symptom of hyperthyroidism. With a high level of metabolism and excess energy the body works overtime and the sufferer tends to burn out.

Strauss (1975) says that when a regimen is successful and symptoms lessen or disappear patients are more likely to adhere to the treatment. He also warns that the regimen's very effectiveness may convince some people that they are cured and can stop their treatment. Only one subject did stop her thyroid hormone, but she did so with her physician's approval and remained under his care. Convinced that she was cured, she discussed stopping her medication with her doctor who agreed to a three month trial period.

Her energy and hormone levels were so low at the end of the three months that she had "all the proof I needed."

Another woman threw all of her of pills away when she was dissatisfied with a physician. In this case, however, she was not at all convinced of being cured and immediately sought out another physician and her thyroid replacement therapy resumed.

Another subject was also tempted to stop her medication after hearing about a hypothyroid friend who was no longer taking Synthroid but was now following treatment for Candida albicans (yeast) infection. Once this subject weighed the requirements of the two regimens (a stringently restrictive diet against taking one pill each day) she decided she was better off as she was.

To sum up then, the regimen is simple. The medication works in that some patients (but only one in this study) appear cured. For others the symptoms are lessened and, once regulated, they function quite well most of the time. However, many people do continue to have fluctuating symptoms and periods when they feel ill.

3. Controlling and Accommodating to Symptoms

Although only one woman in the study stopped taking her medication, and this was only temporarily, all but two subjects were tempted to adjust their dosage at one time or another without consulting the doctor. Of these two, one was very aware of the cyclic nature of her symptoms and recognized that by the time her blood levels could adjust to

a changed dosage her symptoms would have already swung back, and that would only necessitate a readjustment. The other has reduced her dosage twice with prior permission from a doctor and has not seen a doctor for over three years. Before moving to Edmonton, she had started on a relatively high dose and was advised to cut back when palpitations occurred. This she has done twice and her dosage has stayed stable for two years now.

Most of the remaining subjects have only changed their dosage a few times. This was usually to increase it when they felt hypothyroid symptoms were returning. Their opinion is that physicians will readily reduce their dosage in the face of signs of hyperthyroidism but are reluctant to increase the dose. Although they had increased the dose, several were afraid of taking too much. They had been warned of cardiac complications. Two said they had tried to change their daily dosage but had given up because the tablets crumbled instead of breaking neatly in half. Many commented on the long lapse in time between changing the dosage and feeling an effect and almost all subjects wished for a medication that they could control according to the way they feel.

Another had less difficulty breaking her tablets (which may be a different preparation) and said she "wasn't afraid to play around with it". For some time she alternated between taking one pill for a few weeks until she was getting too tired, and then increasing her dosage to one and

a half pills until she started getting headaches. Eventually she settled on one and a quarter pills per day.

The subject who was taking Proloid believes its effect on the body is shorter and, after some disagreement with doctors, she now adjusts her medication independently. She says she feels more in control:

> ...I find that if I feel I'm getting in the hypo stage I just take an extra quarter or a half and I build myself up. Whereas the other pills (Synthroid) I have to go in to see the doctor, take my blood test...then it takes me another month or so to get up again. I find these a lot better....I do go to see my doctor and sometimes I'll ask him in so many months if I could have my blood tested. But most of the time he tells me I'm hyper and I don't agree with him. 'Cause I tell him if I cut down on my dosage I start getting short-winded and very heavy breathing and then this pain comes in the chest. So he agrees with me now that that must be, you know, getting hypo.

The above story illustrates a predicament many of these women face. Bothered by symptoms, their thyroid tests nevertheless measure within the normal range. Physicians confront the same dilemma. Should they increase the dosage until the patient feels better (as was done before thyroid hormone measurements were readily available) and risk added wear and tear on the body, especially the heart?

Several subjects offered an opinion that, perhaps, each individual's normal range was slightly different and that the standard range didn't apply to everyone. (Recall that Evered [1976] drew attention to this fact.) One subject said:

> It's that sense of I must be crazy because I'm experiencing something which people are saying I shouldn't be experiencing. I'm experiencing fatigue and my doctors say to me, "But your thyroid test is

> fine." And you're saying, "If it's fine but I'm having all these symptoms, how can it be?" And really in fact maybe it isn't fine. It's just that they're at the lower scale, okay, and maybe their physician doesn't know how to read the test for somebody who has a thyroid problem, which my own physician acknowledged only this year. He said, "I used to think that as long as you were in the normal scale, or if my thyroid patients were in the normal scale, they were fine. Why are they complaining about those symptoms? It must be something else. Until I finally realized that they, if they are in the lower part of the normal scale, they're beginning to have symptoms, whereas, if I try and keep them on the higher part of this normal scale then they feel better." You know, he said to me, "I suddenly started listening...and began to say, no, when I see a thyroid test of a thyroid patient and it is in the lower half, I'm not comfortable with that. Whereas if it was the normal Joe Blow coming off the street who doesn't have a thyroid problem and it's maybe in the lower half of normal, I'm not going to be as concerned."

As well as trying to control their symptoms by controlling their medication, people with chronic illnesses also need to redesign their life-styles to counteract or to accommodate to symptoms that develop each time their trajectory slopes downward. Prior to diagnosis most women with hypothyroidism have devised ways of dealing with their symptoms . Most of these are simple measures to alleviate symptoms: hot baths and dressing in warm clothes, lotions for dry skin, extra rest for tiredness, and not driving when tired. Some of these measures may no longer be necessary once treatment is established, but most women in this study experience periods when old symptoms reappear or residual ones worsen. They learn to accommodate to their cyclic reoccurrence of symptoms and having established ways of dealing with them in the past, can reinstitute counter-

measures when symptoms reappear. This is illustrated in the following quotes:

> I don't trust my memory anymore, my short-term memory. So I tend, especially if I start feeling a little bit down, I never know if I'm down because of thyroid or something like that, so I immediately click in my little trigger system where I write everything down. And I just, you know, I'm just meticulous about notes.

A receptionist said:

> ...you know how you get two or three phone calls in a row? Well, if you get them fast, you'll write down just maybe an initial or something and go back and try and (write it out later). I can't do that. They can stay on hold for all I care now, because otherwise I ruin my credibility totally because my messages will be completely wrong.

Work schedules, however, do not accommodate to the sufferer's periods of tiredness and low energy:

> So I tried to develop some coping mechanisms that would work. I learned to say no. I say no well. I have some relaxation kinds of mechanisms that, they're very simple. They're the ones that I find work. But, and they're probably connected with the fact that when you are hypothyroid you have to have times when you can be totally relaxed and rest because otherwise you get too tired. And so sometimes I just take what I call a "veggie day" on a Saturday or a Sunday. And I just do nothing. I take my book. I read. I sleep. I poke around all day in my housecoat and that seems to help. I learned to sort of relax, to make myself relax, to stop, to relax, you know, doing the breathing bit and the muscle relaxation bit and just forcing myself to relax and that helps. Because the stress you can't avoid. It's there. And you learn to live with it and adapt. And it serves me reasonably well.

One lady laughingly told of her ingenious solution to being cold all the time, but having a husband who wanted fewer covers on the bed:

> So I decided I'm going to buy two single bag comforters, you know, duvets. One very thin for him and one very big one for me and I'm going to sew them

> up the middle and stick them in the cover and he can have the thin side and I'll have the thick one.

Several mentioned the need to take frequent naps, to go to bed early and to pace their work, to tackle the harder jobs and those requiring extra concentration in the morning. Many learned to accept lower standards for what they could accomplish and so expressed the need for setting priorities:

> I can honestly say I never was hindered that I couldn't do anything, but if I did something then I didn't have the energy to do something else. I took my kids to their soccer games and whatever activities they were in, but something else got left behind because of that. And if I decided this was my day for cleaning house, well then I couldn't do much else. You know, its a trade-off. You pace yourself. You say, "I can do this but I can't do that today.

Such domestic rearrangements are only satisfactory when a person's family, especially her husband, approves and is willing to make up the shortfall. Most of the subjects described husbands who were very supportive and helped with cooking or other domestic duties. One woman described her family this way:

> They're very good. They help me any time that I need help. But that, that's not the issue. I wish I could do it myself, you know? I want to be the same as everyone else and have that boundless energy that everyone seems to have.

Other subjects emphasized the importance of developing a positive attitude towards what they were able to do, in order to avoid feeling negatively about their limitations.

When symptoms are potentially stigmatizing, husbands and other empathetic people can help to minimize their effect. One extended family with several hypothyroid sufferers jokes about their forgetfulness. Another husband

is primed to greet friends loudly by name and so prevent his wife's embarrassment.

For three of these women insomnia is an ongoing problem and has lasted several years. The fourth woman has been on thyroid medication for one and a half years and is still far from well-regulated. Two of them have been taking sleeping pills for several years and one is being followed at the Sleep Disorders Clinic at the University. The last woman thinks her insomnia coordinates with times when her own thyroid output is particularly low. During her first relapse and before increasing her Synthroid she became depressed and afraid to sleep:

> And I'd be there and I was so tired but I was fighting my sleep because I kept thinking if I, this feeling would come over me, and I'd feel like if it hit my knees I was going to die. And I couldn't let it hit my knees. And I remember I'd jump up when it got to about my waist or just below my waist, 'cause I'd think, "It can't. I'm going to die.: And I'd sort of jump up and I'd sit there and I'd be like, groggy-eyed and I'd try to move...I can't explain why I had these feelings.

Symptom control is an ongoing challenge for women with hypothyroidism. After the medication treatment is established many symptoms resolve but some only lessen in severity. Some symptoms are periodic continuations of pre-diagnosis symptoms and reappear from time to time. This means that many women with hypothyroidism must constantly monitor their changing symptoms and modify the routine, and so must their families. Many of the residual symptoms are perceived as annoyances with which one can deal if one is prepared.

4. Adjusting to Hypothyroidism

As previously stated most people with hypothyroidism greet their diagnosis with relief. At last there is an explanation and a treatment for their illness. With treatment they expect to feel better, and they do -- but not immediately!

Thyroid medication takes several weeks to build up to a therapeutic concentration in the body. Symptoms receded quickly for only two subjects, the mildest cases. Case number 10's tiredness disappeared "not too long" after starting her medication and Case number 11's lump in her throat was gone in about three days. The rest only began to notice some relief after anywhere from three weeks up to two months. One lady told of doing more in the first three months than she had done in the last three years but, for many of these women improvement was slow and discouraging:

> I didn't feel good for about a year! Yeah, that was really tough. I thought, well, you know, in a few weeks I'm sure I'll feel better and-a it just didn't happen. I think I was so worn out that it just took so long for my system to build itself up again. I don't know, I can't explain it...but it did feel like there was something in my throat. And that's gone now but it took about a year for that to disappear after I was on meds.

One subject didn't begin to feel better for three to four months and took two years to "really build up". Another spent two and a half years finding an appropriate level of Synthroid. Another, after one and a half years, has not yet been regulated on a maintenance dose. She has just changed physicians and at the time of the interview had

been advised to stop taking Synthroid for a few weeks of reassessment after which the doctor would start her again and monitor her closely.

Unlike the downward course of many chronic illnesses, the initiation of hormone replacement therapy turns the trajectory for the hypothyroid sufferer upward towards recovery. From a low point at diagnosis the trajectory traces a slow but positive climb, marked by an uneven route of periodic exacerbations and remissions.

5. Normalizing Life Style

A chronic illness challenges its victim to try "to live as normally as possible despite his symptoms and his disease" (Strauss, 1975:58). For the hypothyroid sufferer on a recovery trajectory the need to appear normal and manage the impression she projects to others lessens as she becomes better regulated on medication, but it doesn't disappear. Symptom persistence and periodic recurrence compel the sufferer to constantly monitor and manage her illness state.

a. Health Promotion Behavior. For the ill person, normal equates with healthy. Consequently, many hypothyroid sufferers engage in behavior that promotes overall health. Preventive health behavior may result from a desire to influence her own disease process or from general societal increase in health consciousness. Either way the hypothyroid sufferer benefits. Taking more responsibility

for her health restores a greater sense of control over her illness.

> I take care of myself as much as I can...I know that I need, as everybody else, I need a healthy diet. I need, because of my spasmodic colon, I should be having a high fibre diet and I try. I know that I should be having exercise and I try. Some years I do. Some months I do better than others. I think taking care of myself is not a response to the thyroid problems although I know it helps the thyroid problem.

Several respondents spoke of the importance of exercise and good nutrition. Some specific measures like a high fibre diet to counteract the tendency toward constipation resulted directly from their symptomatology. More general examples of diet control included cutting down on fats, coffee, and sugar; and increasing fruits and vegetables. Taking vitamins and mineral preparations as a supplement to modern highly processed foods was advocated by one respondent. Another had recently attended a wellness conference. In addition, she said:

> I've cut down on alcohol a lot because I find I just feel so terrible that I think, "Well, why do I want to bring myself down any more?"

Beyond general health promotion, living normally in spite of one's chronic illness necessitates a good understanding of that illness. Belonging to a self-help group helps many ill people to learn more about their illness.

b. The Thyroid Foundation of Canada. Ten years ago the Thyroid Foundation of Canada was formed to raise public awareness of thyroid disease, to foster moral support for sufferers and their families and to raise funds for thyroid

research. There are now eleven chapters in Canada. Nine subjects in this study belong to the Edmonton Chapter, reflecting on the method of sampling rather than the ratio of Edmonton thyroid patients to membership. Despite the political orientation of the national goals, these women joined for more personal reasons, to learn more about their condition[1] and to receive support through the sharing of experiences.

Patient education appears to be the main thrust of the Edmonton Chapter and meetings center around a guest presentation, usually by a physician, on some aspect of thyroid disease. Several subjects spoke of the dearth of publicly available literature. The Foundation's pamphlets, written in layman's language, are helpful. Several subjects stated that doctors may not keep up to date about thyroid disease and "the chapters are getting into depth." Recommending membership to anyone with hypothyroidism, one woman said:

> I think they're doing a great job. I see new members all the time who come and who are so lost who really, "Hey, what happened to me? The doctor said I have this and I have to take this pill for the rest of my life, but I don't know what's wrong with me." And they can't accept it or believe it or just simply don't know what's going on, and it's a big help. So I would recommend that.

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1 A survey of the Thyroid Foundation of Canada found that learning more about thyroid disease was the primary reason for joining. In descending order of importance, other reasons were: to help others find out more, to encourage research, to meet others with similar problems, to increase public and medical awareness of thyroid disease, and to socialize (Hudacin, 1985).

The hypothyroid patient may have particular difficulty accessing whatever public information is available. The monthly meetings provide a ready-made opportunity to learn about her disease. This point was well-made:

> But when you're losing your self-esteem and that, it's pretty hard to be assertive and find other answers. That's why a group like the Thyroid group is so important.

After the strain of hiding your emotions from others and "hating to talk to anyone about your illnesses" in order to preserve social relationships, it's a relief to find people who understand and want to talk openly about your problems. Discovering others who share your experience has been called "the validation of experience" (Leventhal, 1975:127). While meetings provide professional speakers to teach about the disease, those who share the experience can provide role models for coping with the illness. Through social comparison the sufferer can evaluate her own experience, learn coping skills and avoid the fear and pitfalls others have overcome. Equally important, helping others affords the helper an opportunity to re-evaluate her own situation and build her self-esteem (Farquharson, 1981).

An interviewee criticized the Edmonton chapter's educational focus at the expense of its support and self-help function. She observed that the formal lecture style of many presenters discourages questions and the sharing of experiences. She felt that group discussions should be incorporated directly into the meeting format rather than leaving them to the end when not everyone is able to stay.

She said that although education is important it is more important to "validate through support our experiences."

> ...I think that it should be more of a support than just an educational association and it has been an educational one. And again, I get very frustrated because...what I've seen in the association is a place where doctors can come and speak and tell us what's right.

An important social benefit of self-help groups can be the opportunity to overcome the isolation imposed by many chronic illnesses.

6. Dealing with Social Isolation

Plagued by tiredness, depression and other potentially stigmatizing symptoms the person with hypothyroidism often finds it easier to withdraw from social relationships than to risk embarrassment. Lack of energy forces the ill person to concentrate on work and home life leaving neither time nor the inclination for social activities. When, as a result of her symptoms, the ill person's personality and interests change and when their invitations are turned down or not reciprocated, friends gradually withdraw from the ill person. This is especially true when her illness is interpreted as psychosomatic (Charmaz, 1983b).

Women with hypothyroidism experience social isolation especially if they have had a long illness before diagnosis and treatment. Once they begin to recover they may try to repair damaged relationships, but even then residual and cyclic symptoms frustrate their ability to do so.

Memory loss is particularly troublesome in social situations and makes the person self-conscious. In the words of one subject, "I'm not sure I'm not going to blow something." Another avoids social situations because she can't remember names.

> It's embarrassing to have to walk in and, "Hi, how are you?" and give a big hug and a kiss and shake hands when you don't even know the person's name 'cause you can't remember it.

I asked whether she had had the same problem before her illness.

> Oh no. I could remember names well enough that I didn't embarrass myself every day. I mean, it happens at least once a day and frequently three or four times a day. It's bad, but it's something I've got to live with and I can handle it.

She explained that sometimes the best way to handle it is to be forthright:

> Oh, and my speech is bad too. I go to say one word and another one will come out. Like the connections between the brain and the tongue is gone somewhere. Sometimes it can be just perfect and then another time I'll make a damn fool of myself. And after you've done that a few times, you just say to people, "I stumble over my words. That's the way I am." You know, you just admit to it because there's no sense trying to hide it. I tell people, "I'm not going to remember your name in five minutes. It's not because I don't like you. It's just that my memory is really bad."

Chronic tiredness and lack of energy and the need for more rest-time reduce the time available for socializing:

> I know I can't stay up late. I'd love to go out and stay up. Well, I did when I was younger but, you know, in the last nine or ten years, I know if I go out then I'm really going to feel rotten the next day...I look at my husband and he's a few years older than I am but he can do it. And I think, "Why can't I?"

Some subjects entertain less than formerly. One said her husband pitches in and does half the cooking. Not knowing how she is going to feel makes it hard for some women to plan social activities because when the time comes they may have to back out.

Many find they are unable to participate in formerly enjoyable activities:

> ...I can't keep up with them in sports. Like they can go out and play tennis. Well, I can't. I've learned to pace myself. And I know what I can do and how much I can do, and that's it.

> I'm a born shopper. I can go look in the mall there for hours. I used to be able to walk for hours and just look and, you know, and wish and want and everything. Now I can't be bothered. To go to work, to go grocery shopping that's it. To get energetic, my husband is an outdoors person, a sportsman and I just hate it when he asks me to do something now. I do it because, I mean, it's not fair to him either, you know? But I hate it because I just don't have the energy. And I think that's probably why he doesn't ask me a lot, 'cause he knows I just can't keep up...and I always used to love doing that kind of thing.

One subject even blamed her son's shyness on her inability to take the children out more. Now that she is feeling better, she and her son are enrolled in a mother/pre-schooler gymnastics class:

> My daughter does fine in school but my son, I'm taking a gymnastics class with him and now he refuses to go. He does not want to go, does not want to participate. I think I always question, "Well, is it because of, I wasn't taking him out before as much, or I wasn't interacting with people. I was just sitting here at home, you know, in my gloom...I think I feel guilty because would he have been this way if I hadn't had that illness?

Most of the study's participants talked about their "down" days and their "up" days depending on how the thyroid

was functioning. When many people begin thyroid replacement therapy, they have some functioning thyroid tissue. When their own gland kicks in or shuts down, the level of hormone in their blood may be too high or too low. Fluctuations may also occur when the sufferer with complete thyroid failure or a complete thyroidectomy, who is on a stable dose of thyroid hormone, experiences changes in stress or activity and requires a change in the circulating hormone level to deal with it.

As a result, many subjects find that their social life appears to fluctuate with their thyroid. As one said, "When I'm really down, I'll get myself in a corner." Although some friends may drift away, others are willing to "tag along until you're better."

7. Obtaining Funding

Financial considerations are less problematic for these women than for Strauss's (1975) chronically ill people. Yet finances do constrain one's options in managing illness despite the provision of universal health care insurance. Health insurance obliges one to use the services covered; alternative kinds of care, if desired, are expensive. As services that are considered nonessential become increasingly rationed, financial constraints are likely to become more significant. Similarly, being ill may constrain one's ability to earn.

Repeated medical appointments can be difficult to justify to one's employer and the necessity of working makes

it difficult to comply with a physician's advice to take a holiday. Women in this study lowered their aspirations for career advancement due to their requirements for more rest and less stress, and one found that she was able to manage part-time work but not full-time.

The above evidence shows that hypothyroid women respond well to thyroid hormone replacement and most are considerably better once a stable dosage is established. Thyroid medication remains a treatment however, not a cure and complete recovery is elusive. In order for the hypothyroid sufferer to achieve complete validation she and her care-giver need to agree that she is receiving the optimal amount of hormone replacement to ensure an optimal level of recovery. Several barriers can block such agreement.

B. Barriers to Complete Validation

Several barriers to complete validation could be isolated from these women's stories. They include misdiagnosis, the difficulty associated with regulating thyroid hormone replacement medication, symptoms that remain after she is regulated on the medication. Two other barriers are encountered by the woman whose doctor defines her illness trajectory differently than she does or neglects to teach her about hypothyroidism.

1. Misdiagnosis

Hypothyroidism's propensity to copy other diseases (Acute Care Medicine, 1984; Klein and Levey, 1984) leads to the possibility of being misdiagnosed. Five subjects in this study were given a different diagnosis prior to hypothyroidism. One was treated for depression and manic-depression and a second for tendonitis and psychiatric problems. The third had migraine headaches and haemorrhoids and the fourth received medications for depression and menopause. Another was treated for depression alone. Each of these women feels that the symptoms associated with the former diagnoses improved once she was given thyroid hormone, although one continues to be treated for periodic tendonitis.

Although she denies any symptoms of manic depression at the time, one woman was treated with Lithium for almost a year in her early twenties. She had also been given anti-depressants four years earlier. She admits to depression that was partly situational and that "there was at least one time in my life where it seemed like I was, perhaps, somewhat manic, in the sense that I had more energy than I ever had before." On both occasions she stopped the drugs without her doctor's consent. Except for flattening her affect, which she didn't like, she remembers having little

response to the Lithium, but she questions it's effect on a subsequent pregnancy.[2]

> ...I was off the Lithium about a month before I got pregnant. My child died. [said very slowly and deliberately] And it was mid-labor when they realized something was wrong, and she did not survive. I never did see her. She survived for twelve days but I didn't see her. She was [had] quite a bit of abnormalities of which they don't know why, and there is this slight idea that maybe [it was due to] the Lithium, because it would have still been traced in the body, or whatever.

Whether this woman was manic-depressive and the Lithium caused her hypothyroidism or she was experiencing a hyperthyroid swing and diagnosed with manic-depression is a question. She still experiences cyclic symptom change but the magnitude of the changes from high to low decreased markedly after thyroid hormone treatment was established.

About a year before her diagnosis one subject banged her elbow on the cupboard. Tendonitis developed and eventually both shoulders froze. The anti-inflammatory medication was discontinued when she began bleeding from the bowel. Seven months of physiotherapy eventually resolved her discomfort, but she continues to have occasional problems.[3]

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2 "Since adverse effects on reproduction have been reported during the course of animal studies, Lithium should not be used during pregnancy or in women of childbearing potential unless it cannot be substituted by other appropriate therapy and the expected benefits outweigh the possible hazards to the fetus" (Compendium of Pharmaceuticals and Specialties, 1988:494).

3 This lady is also diabetic. Diabetes, rheumatoid arthritis and hypothyroidism can all have an auto-immune etiology.

Following a partial thyroidectomy one subject was treated with strong analgesics for severe migraine headaches before a second thyroidectomy was performed ten years later for a malignancy. Between the two surgeries her constipation caused haemorrhoids and a haemorrhoidectomy was done. One could question whether the constipation was a side-effect of her analgesics or caused by hypothyroidism and increased by the analgesics. Thyroid hormone replacement was initiated following the second thyroidectomy and both her constipation and headaches cleared up.

The remaining two women were treated with anti-depressants. One woman was helped for a few weeks before the effect wore off. The second woman had severe menorrhagia that was terminated by a hysterectomy. Following the removal of her uterus she became depressed and states that the antidepressants helped for the first three months. She believes her hysterectomy might have been averted had a physician diagnosed hypothyroidism sooner.

For the sufferer any feasible diagnosis provides validation for her illness and she begins treatment hoping for an end to her problems. When symptoms persist in spite of the treatment, she begins to question the diagnosis and so may her physician. Because a person may suffer from more than one illness concurrently, it may be unfair to label these cases as misdiagnoses, especially when this research project has not utilized data from the physicians involved or the patients' medical records. From each sufferer's

perspective, however, the prescribed treatments failed to completely alleviate her symptoms and, therefore, either she, her physician or both began looking for a new explanation.

2. Regulation of Thyroid Hormone Replacement

Because patients experience varying amounts of damage to the thyroid gland the dosage of thyroid hormone must be individually calibrated (Bayliss, 1980). In general, a very low hormone level in the blood may indicate the need for a bigger dose, but different people may utilize and excrete the hormone at different rates. Factors peripheral to hypothyroidism such as stress, other illnesses, her weight, and the amount of sleep she has can also influence the body's utilization of thyroid hormone. In addition, thyroxine has a long life within the body so that, for the average person, half the strength of today's pill is still present two weeks later. Therefore, whatever hormone the patient's thyroid gland manufactures plus the remaining amounts of several week's daily medication constitute a person's circulating hormone concentration. For all these reasons hormone replacement regulation is a complicated matter and the optimum concentration must be built up gradually.

In addition, those patients whose hypothyroidism has developed quickly can be safely treated with higher doses. Those with long-standing myxedema must begin with very low doses, in order to avoid serious cardiac complications, then

increased or decreased at six week intervals depending on the laboratory results and the patient's response. If palpitations occur then the doctor must decide whether to decrease the dosage or whether these are "intermittent and innocent palpitations" (Bayliss, 1982:77) that will disappear as treatment becomes established. Thus, finding an appropriate stable amount of thyroid hormone usually is a time-consuming, but carefully managed, trial and error process aimed at relieving symptoms, reducing the TSH to normal and achieving a blood thyroxine level in the mid to high normal range.

Patients need to be warned to look for hyperthyroid symptoms that indicate too much hormone and also of how long before a noticeable effect will appear. When patients are assured of results within two weeks and nothing noticeable happens, then treatment can be very discouraging:

> ...and I asked him when I could expect to feel better and he said, "Almost immediately." I was ecstatic! I didn't feel good for about a year! Yeah, that was really tough.

On the other hand one woman was told that recovery would take a year but was told little else:

> ...but it's not a fun thing to try to go through and, like I say, if only you could get somebody just to listen sometimes, you know? And have some sort of support there, you know, that this isn't going to carry on. Your swelling's going to go down and your mood swings are going to slowly go away. You're gonna feel better. You're gonna. Not just tell me I have Hashimoty's (sic) Disease and that's it. You know? Um, telling me a year from now I'm gonna be better doesn't help me, doesn't help me at all.

3. Residual and Cyclic Symptoms

As we have already seen, not all hypothyroid patients recover completely. In this study almost everyone continued to experience symptoms, most of them in periodic cycles, albeit of reduced severity (Tables 9 & 10).

TABLE NINE

REPORTED PHYSICAL SYMPTOMS WHILE ON THYROID HORMONE TREATMENT

Symptom	Subject 01	02	03	04	05	06	07	08	09	10	11	12
Tiredness, Fatigue	*	*	*	*	*	*	*		*			*
Dry skin, Rash		*		*	*						*	*
Weight problems					*				*			*
Menstrual irregularity						*			*			
Hair loss, Dry hair								*				*
Constipation	*								*			
Palpitations												*
Split nails				*	*				*			
Heat intolerance	*						*				*	*
Cold intolerance	*			*	*			*				
Exophthalmous				*								
Arm or leg pain +		*			*							*
Headaches	*											
Frequent colds								*				
Diarrhoea	*											
Anaemia	*											
High cholesterol												*
Burning eyes									*			
Contact lens discomfort					*							
Intolerance to alcohol							*					
	01 #	02 #	03 #	04 #	05 #	06 #	07 #	08 #	09 #	10	11	12 #

\+ described variously as tendonitis, leg cramps and tingly fingers

\# cyclic symptoms

Continuing symptoms may tempt the sufferer to increase her medication or request that her doctor do so. Bayliss (1982:78) suggests that some patients become "addicted" to hyperthyroid doses of thyroxine and "persist because the

heightened dose increases their energy." As this woman recounted:

> ...I upped it quite high too. Yeah, I could run like the wind, but my heart must have been going awfully fast. And that's what the neurologist said when I went back there. He tested my thyroid and he said, "It's too high." And I said, "But my memory's coming back." And he says, "But you're going to have a heart attack!"

TABLE TEN

REPORTED PSYCHOLOGICAL SYMPTOMS WHILE ON THYROID HORMONE REPLACEMENT

Symptom	Subject 01	02	03	04	05	06	07	08	09	10	11	12
Depression		*		*					*			
Labile emotions								*				
Short-term memory loss	*	*		*								
Problems concentrating		*		*				*				*
Insomnia				*				*	*			*
Lack of motivation				*								
Anxiety				*								
Poor self esteem		*										
Premenstrual tension									*			
Jittery, Restlessness	*						*					

When physicians explain the trade off between completely obliterating her hypothyroid symptoms and the dangers of inducing hyperthyroidism, their patients are more likely to respond reasonably. This patient continued her story:

> He didn't tell me to stop taking them. I'm not totally stupid. I didn't cut it out. I cut it down over the space of a couple of weeks until I got down to, I think it was .03, well .3, pardon me.[4] And then I went to Dr. (name of her regular doctor).

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4 The CPS (Compendium of Pharmaceuticals and Specialties, 1988) gives the usual adult maintenance dose of Synthroid as .1 to .2 mg. per day. Bayliss (1982) recommends .15 to .2 mg. for an adult with no functioning thyroid tissue. She

Allopathic medicine's success with many acute illnesses has fostered a belief in the ability of medications to cure disease. This story of a woman's diagnosis was repeated by several interviewees:

> ...and when I came in he said that my, I don't remember which tests they were, he said that it was so low, he said, "It's amazing you're walking around." And he said, "but there's a cure." And he put me on medication and he said, "Come back in two weeks and you'll feel much, much better. But I didn't. It takes a long time to build up in your system. Not two weeks as some doctors would like you to believe.

In the same way that doctors expect to cure patients, the patient expects to be cured when she consults her doctor. Taking on the sick role (Parsons, 1951) obligates the ill person to cooperate in the process of getting well. If a physician neglects to prepare his patient for a slow and often incomplete recovery, she may even blame herself for her inability to recover.

> ...and I found that the medical profession said, "Oh, this is just a real little simple problem. Here's your pill, now you'll be fine." But I wasn't fine, so then it had to be me...my self esteem was so low by that time that it, I was this little housewife with this little tiny problem, you know, and that it wasn't very serious and because of their attitude that it was not a big deal.

Strauss has observed that "all chronically ill people who have partial recovery trajectories or oscillating better-and-worse periods necessarily run the hazard of others discounting their quite possibly slow recovery" (1975:63).

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may require .25 mg. occasionally, and rarely .3 mg. per day. This woman *reduced* her dose to .3 mg. per day.

4. Differential Definitions of the Trajectory

Coming to terms with her remaining symptoms requires that both the sufferer and others accept that thyroid hormone replacement only treats and is not necessarily a cure, and that they agree about what constitutes an acceptable degree of thyroid functioning. An ill person has problems socially when others define her illness differently than she does. They may treat her as an invalid when she is capable of doing things for herself. More commonly with hypothyroidism they expect her to do more than she feels she is capable of doing. She feels torn between others' expectations and her need for rest, and hurt when other people imply that she is lazy or anti-social.

Nevertheless, women in this study were able to excuse their families and friends for not understanding the extent of their illness better than they could their doctors. Many were angry at physicians whom they perceived as dogmatic and unwilling to listen or treat their patients as individuals.

> We're all different and they don't realize that. They go by the book standards and that's not right, you know? Maybe my thyroid count should be higher. It's a possibility.

Another woman agreed:

> I don't think it's a textbook disease and that you can really say, "This is it and this is what it does and this is what it doesn't do, and all people will have this problem and all people will have that one, you know? As much as some medical people would like to believe it.

Several have found that doctors discount their fluctuations in energy and other cyclic symptoms once they are on hormone replacement:

> ...he's pretty well told me that there's no such thing. Like, when you're on your correct dosage it's just like your body's producing enough on its own and I'm probably imagining it. But I don't think so; I really don't. And now I know that eventually I'll sort of snap out of it. But I go for weeks where I'm really tired and then it'll be several months and I feel really good and then it comes again.

She was unable to correlate her tiredness with stress or premenstrual tension or anything else. When she told her doctor that she also had hair loss every six months or so, his only comment was, "Well, animals shed in the spring."

Patients don't know who to trust when their doctors disagree with one another:

> ...I have inflammation of my muscles and I have seen a rheumatologist about it and she thought, perhaps, that was also affected by my thyroid or part and parcel of that. Anyways, she had suggested raising the medication just, oh I wouldn't even know what the next step is, but just, just a little bit. When I went back to my own doctor he disagreed. He said, "No."

Consequently many of the subjects conclude that knowledge about thyroid disease, especially its effects throughout the whole body, is limited. They believe that thyroid deficiency is more common than many physicians acknowledge and that not all doctors are aware of recent advances in understanding it. In the words of one subject:

> Probably the biggest thing is education for health care professionals because most of them don't understand that there's a lot more to that disease than just the fact that you don't have enough thyroid hormone...there are several different types of hypothyroidism, that it is not just your thyroid gland not functioning properly. Your thyroid gland may be functioning fine,

> but there may be other things that aren't functioning. It's a disease that not much is known about. You probably knew this anyway but I think education, when we are teaching nurses and doctors and whatever, they need to recognize that this is a common disease.

Much of the misunderstanding boils down to a lack of clear, bilateral communication between doctor and patient. Equating a good doctor with one who takes the time to listen was common in these interviews. Most subjects subscribe to Roberts's (1985) observation that "the patient is the expert on what it is like to have her own illness. These beliefs may translate into their choice of doctor. Some believe a woman doctor will be more empathetic and willing to listen. Some find that general practitioners are inclined to give them more time; others that specialists, with perhaps more experience with the disease, can be more empathetic. In the end a good relationship with her doctor appears to rest upon his listening to her illness experience and, hence, her perception that he treats her problems as unique. One subject put it this way:

> I always find it very difficult when physicians, or any kind of people that seemingly have some knowledge invalidate your experiences. I feel that that's a professional thing and we need to be able to...at least validate the person's concern and see why they would have that concern and check into that...Not simply say, "Oh, you're just another ignorant person." I find that hard. Which I think with the thyroid problems that happens a fair amount.

Many also think that a visit to the doctor should include more patient teaching about the disease.

5. Lack of Resources for Learning About Hypothyroidism.

Besides the lady who learned about hypothyroidism from her holistic doctor, only three other subjects credited their doctors with teaching them about hypothyroidism. Another subject was able to purchase a book from her doctor but he didn't discuss it with her. One nurse's doctor explained nothing, probably because "he knew that I was a nurse," however, another assumed that her endocrinologist gave detailed explanations because, being a nurse, she could understand the pathophysiology.

Thyroid disease, particularly auto-immune thyroid disease may be quite difficult for many patients to understand. Although her doctor explained Hashimoto's to her, one woman said that she really didn't get it. Another, when discharged after her thyroidectomy was told she had Hashimoto's:

> And he says, "You know you have Hashimoty's (sic) Disease and you will never get rid of it. And I said, "What is that? Is it communicable or, like, what do I have?" And he goes, "No, it's only you that has it. You can't pass it on to anybody or anything. It's just you." And I says, "What is it?" And he says, "It's just a condition of." [I said], "A condition of what?" And he said, "Well, your thyroid." And then he left. And I'm like, "Well, wait. I want to know more here." So then...I went over to the clinic and I said to the doctor there, I says, "I have Hashimoty's...What is that?" And he goes, "Well," he says, "That's the tired stage that a thyroid will go into." And so I thought, "Oh, okay." And I says, "Well, what do you mean?" And he says, "Well, first there's," he named the first two stages off and then he said that, "It's Hashimoty's." And he says, "It's just a condition."

Lack of information can also initiate doctor-shopping. Just before her interview the above lady began seeing a new doctor who she expects will be very helpful.

Structural aspects of the doctor/patient relationship are partially responsible for this lack of patient teaching. In a brief visit little time is available for comprehensive instruction. In Kleinman's (1978) study allopathic physicians spent, on average, only forty seconds explaining to their patients; Waitzkin (1985) measured explanation time as 1.3 minutes, about nine percent of the visit's length. This contrasts with 8.9 minutes, the mean amount of time that doctors in the Waitzkin study estimated that they had spent informing their patients.

Although doctors may be constrained by the demand for their services or the desire to maximize income and so provide short appointment times, social control theorists explain that communication is blocked between physicians and patients by a grossly unequal balance of power in this hierarchical social relationship (Pirie, 1988). They propose that doctors control the amount of information passed down to their patients as a means of preserving their power.

Roberts (1985) observed that doctors are more likely to give fuller explanations to their better educated patients. Studies of the doctor/patient relationship show that physicians generally underestimate the amount of information that patients desire (Waitzkin, 1985), the amount of general

medical knowledge they already possess (Pratt et al., 1957), as well as their ability to understand medical terms (McKinley, 1975, cited in Wallen et al., 1979).

The doctors' impressions may be reinforced, however, by their patients' tendency not to ask questions. Waitzkin (1985) found that patient's spend, on average, only 8 seconds, one percent of the total available time, questioning the doctor. While women appear to ask more questions than men do, they are much less likely to receive an explanation that is of the same level of technical sophistication as their questions (Wallen et al, 1979). When this happens, women may either be unable to understand the answer or that feel they are being treated childishly. Suffering with cognitive dysfunction and depression, women with hypothyroidism are probably even less likely to assertively question the doctor than the average woman.

Patients can only be expected to take responsibility for their own health if they are properly educated in health matters (Roberts, 1985). The reality of patient teaching is far from the ideal for good health care as advocated by Eisenberg:

> The doctor's task ought still to be to educate the patient about the meaning of the illness and the methods for its remedy, after he has learned the patient's conception of its cause and how it might be treated. The process is one of exchange of information, the goal is the demystification of medical procedures, so that the patient is able to make his own decisions and thereby assume responsibility for acting (1977b:237).

C. Outcomes of Cell III

1. Patient Satisfaction

The fact that each subject in this study expressed some satisfaction with her treatment measures her evaluation of that treatment and the validation she received of her illness experience. Being satisfied with treatment appears to depend more on improvement and coming to terms with her residual symptoms than upon being totally free of symptoms. Only one subject judges her level of functioning to be about equal to her pre-illness state. Most others were satisfied with their hormone therapy and had come to accept a fluctuating level of thyroid functioning because it was greatly improved from their pre-diagnosis states.

Some subjects related their acceptance of residual symptoms to regaining a feeling of control and a belief that they can live a normal life. Acceptance comes when a person begins to know her illness and what to expect. It takes time to recognize that, although her thyroid function fluctuates, the highs and lows come less often and don't last as long.

> ...and then I'll know that after a week or so that will level itself back up again. And so, you know, I'm really quite comfortable with my level of thyroidism now.

Another said:

> But now since May I'm a lot better. Fluctuations still, but definitely better...Not as many downs, you know. I'm more even. I do get highs and the lows, if I get them, they're not as long. And the respiratory infections...I haven't had one now since January.

As well, some attributed their satisfaction to a good doctor. An example follows:

> ...and so, I was very lucky in that sense that I had found a couple of physicians who were knowledgeable, people-oriented and very willing to teach, and willing to answer all the questions that I had. So felt I had a good knowledge background. And I had a lot of information that certainly isn't in the textbooks. So that I felt satisfied with.

In contrast, two subjects were somewhat dissatisfied, both because of lack of energy. One wished that her energy level could be more consistent; the other believed that her energy would improve if only her doctor would increase her Synthroid above the stable dose she has been on for nineteen years. Nevertheless, these women admitted to some satisfaction with their treatment based on "coming a long way" since being diagnosed. Even the subject who has not yet become regulated feels markedly better than before beginning treatment.

Dissatisfaction often occurs at the times when the illness persists and when symptoms increase. This may happen especially before the individual's dosage of Synthroid becomes regulated. People become discouraged if symptoms persist over a long period, if some symptoms resolve quickly and others hang on, and if their hormone concentration increases to the point of inducing hyperthyroid symptoms. Destruction of thyroid gland tissue may continue long after treatment begins and sometimes an exacerbation will occur long after stable treatment has been established. This means that the patient needs to be able

to differentiate fluctuations that are usual for her and those that are more permanent and require a medication adjustment. Dissatisfaction can also result from misdiagnosis and a lack of confidence in one's physician.

2. Transition from Cell III

Satisfaction and agreement with her physician that her medication is affording her the best possible recovery from her symptoms signifies that the hypothyroid woman has achieved complete validation for her illness. She would then be placed at the top left hand corner of the typology.

Not everyone being treated for hypothyroidism achieves the ultimate level of validation. Dissatisfaction and disagreement about her recovery will make the sufferer of an illness question her physician, his diagnosis or her own illness and will tend to push her into another position and probably into another cell. In most cases, especially with a misdiagnosis, she will move back to Cell II until her physician decides upon a new diagnosis or until she finds a new doctor and he arrives at a diagnosis. In spite of problems with becoming regulated she may continue to have faith in her physician and the diagnosis. In this case, she will move downward and toward the right, but remain within Cell III, while her doctor adjusts her treatment and she continues to monitor its effect. A final scenario describes the patient who disagrees with her doctor and rejects the treatment. This would initiate movement into Cell IV.

CHAPTER EIGHT

CELL IV DENYING ILLNESS

Denial of her illness in the face of her symptoms may seem like a step backward in the validation process, but to the former patient it can represent recovering control of the situation.

A. Strategy for Denying Illness

1. Rejection of Treatment

Only one hypothyroid subject entered Cell IV during the course of her illness. Although it was a temporary measure for her, it did confer upon her the desired validation that she would be able to make the decision concerning treatment and so be in control of her own illness. This is her story:

> He was trying to convince me to go on Synthroid, but I'm not one who enjoys medication and so, because it [the disease] wasn't making my life difficult to function, 'cause it was getting lower but it wasn't getting to the point where I was feeling like I couldn't function well, I refused the Synthroid for approximately a year and a half and I allowed him to continue to monitor, and on my own time tried to learn more about it, and he tried to learn more about it and then finally, after about a year and a half, it had gone to the point where I needed to go on Synthroid because it was beginning to affect my functioning to the point that I realized I couldn't manage without the Synthroid.

One of her reasons for rejecting the medication was that she was still having intermittent symptoms of hyperthyroidism and was worried about the medication's added effect during those periods. She continues:

> ...when I began to go onto medication and that, I felt that I was controlling what I wanted to do. I didn't

> just say to my doctor, "Oh, I need medication. Give it to me." I said to him, "Oh, I need medication? Well, I'm functioning okay right now. I'm not functioning as well as I could be, but I know I'm functioning okay. I'm not sure I want to take that yet. So I'll make the choice as to when I'm ready to take it."

She concedes that she was fortunate to have a physician who respected her need for autonomy. Later, while she was being regulated on medication she suffered a set back when the hypothyroidism became much worse.

> ...and when I did have to get on a much higher dose than that, my physician didn't say to me, "You must do this and if you don't do this, you're a bad person." He said to me, "(her name), it's your thyroid, and the choice you have is to continue feeling this way or to take the medication that treats it. And I know you're concerned about that, but my recommendation would be...." And that is a different way of presenting something and so that, therefore, doesn't make me as angry. So perhaps I feel more self-confident because of my ability to recognize I'm not going to let somebody push me around or tell me that they're the ones that have all the authority. So, from a personal level I don't allow that, or try and not allow that to happen to me. I try and have more control of that.

B. Barrier Against Denying Illness

1. Persistence of Symptoms

When the hypothyroid patient's symptoms persist, or even become worse, they will eventually reach a point where denial of her illness and the need for treatment becomes impossible.

C. Outcomes of Cell IV

Her relationship with her doctor along with how she perceives her symptoms will then dictate a new position within the typology. Continued denial and discounting of her symptoms will move her back to Cell I. If she retains

faith in her doctor and his diagnosis (as the above woman did), then the decision that her illness requires treatment will take her back to Cell III. A lack of confidence in her former doctor, combined with a decision to again seek treatment, will guide her back to Cell II in pursuit of a new doctor, a new diagnosis, a different treatment, or perhaps all three.

CHAPTER NINE

SUMMARY AND CONCLUSIONS

A. Summary

From the evidence presented above "seeking validation" is, for the sufferer of hypothyroidism, a process encompassing recognizing her own illness and negotiating with increasingly authoritative others, until eventually both she and her doctor achieve a shared interpretation that her illness is legitimate and that she is receiving treatment that affords *her* the best possible level of recovery. A cumulative process of achieving recognition, it begins with the individual sufferer and extends outward among her social contacts. It is an ongoing process that, for many if not most sufferers, lasts beyond finding a doctor and appropriate treatment.

"Seeking validation" is a process imposed upon the sufferer by the nature of the illness itself; it is not a freely chosen activity. Because no two people experience hypothyroidism in exactly the same way, the process has common phases but is individualized for each sufferer by her own constellation of symptoms and her distinct social milieu.

Glaser (1978:74) describes the coding family of the six C's: causes, contexts, contingencies, consequences, covariances and conditions, as the " 'bread and butter' theoretical code of sociology." As such, this schema can

provide a useful tool for summarizing this basic social psychological process, "seeking validation".

1. Causes

What determines that the hypothyroid sufferer needs to engage in "seeking validation" for her illness? Ultimately it is the nature of the disease itself. Symptoms that may occur in on-and-off cycles and are vague, subjective, and often insidious in their onset make the illness difficult for the sufferer to recognize and to describe subsequently to others. No single symptom is peculiar to hypothyroidism. Many symptoms can indicate failure of the thyroid gland but each individual may experience only a fraction of the possible bodily changes. Some combinations of symptoms mimic other diseases. Just as symptoms may vary, different people may experience a particular symptom differently. Some of the symptoms are potentially stigmatizing, making the sufferer inclined to hide them from others. As well, the lack of public knowledge about thyroid disease means that the woman with hypothyroidism will have difficulty deciding whether she is ill and, if she is, what she should do about it.

2. Contexts

People live in a social environment. When a woman is ill, her interaction with her husband, children, extended family, co-workers, and friends will change. Despite her illness, but without social validation of it, she can be

blamed for neglecting to completely fulfill work obligations whether within or outside the home. Her illness also affects her network of social contacts which includes the doctor she consults. Just as her illness may affect each person in her social setting, their reactions to her also influence her illness experience. Events within her social environment can mask illness by providing an external reason for her symptoms. An inability to meet her social obligations and fulfill the expectations of others can lead to their discounting of her symptoms and pejorative labelling. Yet, because of the ambiguity of her symptoms she requires confirmation of her illness from these same social contacts.

3. Contingencies

Several circumstances occurring within the social context will affect the process of "seeking validation", although they are peripheral to it. Although not directly tested because this research sample was confined to women, one of these may be the inequality of women in our society. Imbalances in power relations and economic circumstances between women patients and their (usually) male physicians can result in her difficulties in securing both recognition and treatment for her illness.

Physicians who subscribe to the tenets of scientific medicine rely upon laboratory testing to confirm a clinical diagnosis of hypothyroidism. Many sufferers of the illness experience symptoms long before the most common and

financially cost-effective test will record an abnormality. However, a full battery of tests can be time-consuming, expensive and not particularly pleasant for the patient. Therefore patients, their doctors, and the government as the sponsor of medical insurance need to come to some agreement about what constitutes an equitable balance between technological and humane medical care.

4. Consequences

Due to the above causes, contexts and contingencies, the sufferer's attempt to validate her hypothyroidism can be a slow protracted process involving gradually increasing incapacitation. Difficulties in securing validation can introduce frustration, anger, and self-blame. Problems in communicating her illness to physicians can lead to doctor-shopping and searching for alternative health care. The illness can result personally in a reduction in self-esteem; professionally, in a lack of energy and an impeded career path; and socially, with disturbed relationships and social isolation.

5. Covariances

During the time while she is "seeking validation" of her illness, other elements in her life also may vary. Aging affects her expectations for herself, as well as her effect and influence on others and their perceptions of her. Over time she may assume different social roles, taking on new ones and dropping others, and her social milieu will

change. These changes will in turn affect her illness experience.

6. Conditions

The process of "seeking validation" is modified according to different physiological causes of hypothyroidism. Some types of thyroid insufficiency develop more quickly than others. Some types result in progressively worse symptomatology and others in remissions and exacerbations. When hypothyroidism results iatrogenically from surgery or radiation to counteract hyperthyroidism, thyroid failure should be anticipated and treatment initiated before symptoms become severe.

Most of the women in this study anticipate that the necessity for "seeking validation" could be lessened in the future through research and improved education for professionals, as well as the public at large, and as thyroid deficiency becomes more readily recognized. They envision that the ultimate goal of medical research would be to develop a treatment that could mimic thyroid gland production, supplying just enough hormone to maintain a euthyroid state despite periodic changes in the body's physiological requirements for thyroxine.

B. Subjects' Summaries of their Illness

To properly sum up the effect of hypothyroidism on the sufferer demands listening once again to the thoughts of those with experience. During the interviews I asked most

of the women to summarize the effect of the disease upon their own lives. Their responses range from "no effect" for one respondent through quite severe effects for several women. Some examples follow:

> And so for my experience with that, I really don't have much of a story. It hasn't been a problem at all. No, not at all.

> My thyroid condition, it did affect my life. It affected my life at school. It had a lot of effect on my life, my married life, because I didn't know what was wrong. And-um, all the pain and stress I went through, and a lot of it was unnecessary. That's what hurt most too. A lot of it was unnecessary.

> ...what bothers me the most is that, I can say that up until this May, I haven't really been close to the person that I feel I am, and I feel bad for my kids because my daughter...has had three years of a Mom that was not quite there and my son, all his life pretty well. And being a Mom was something that I always looked forward to. And I feel that their pre-school years are such a big chunk that's been taken. And I feel like I've been somewhere else, that it was just an existence...I think that it has taken away that, I would describe it as like, an inner fire, inner torch...I know when I was seventeen or eighteen that I would have to run because I had so much energy that I didn't know where to place it. And I wanted to do so many things. I'd just grab life and do things and I feel that for the longest time that wasn't there, that vitality, that strength. And I'm just sort of starting to rekindle that now and find a direction, because when you live so long as an existence which was what it was, it's hard to start getting goals and planning and have the energy to keep it up.

And from the lady who is still not regulated on her Synthroid:

> It's still not me, but it's better. I'm better than I was before. If I had half...the energy I used to have, it would make me feel better, you know? I mean, I don't feel that I'm an old person, that I should be feeling like my grandmother right now. I mean, what am I going to feel like when I am her age?...She's got twice the energy that I do right now. I couldn't keep up to her. I could never keep up her pace. Never. I know that. It's terrible....I mean, we all have our up

days and down days and stuff but when you go through such bad depressions, you know? I could see where people actually could probably, I don't have the guts, but could commit suicide, because when you have the feelings of not being loved and paranoia and everything like that, it's a terrible feeling.

C. Limitations of the Study

Limitations of this study stem from the small number of subjects, the convenience sample, the qualitative research design employed, and the particular illness it described. In addition, in order to keep the study to a manageable size, males and children were excluded. Finally, of necessity, the study is retrospective. While much of the focus is upon pre-diagnosis experience, identifying the sample necessitates that hypothyroidism has already been diagnosed. Some forgetting of past experience is to be expected, as well as the fact that pre-diagnosis symptoms and their effects on the individual's life tend to be reinterpreted in terms of the diagnosis, her response to treatment, and to later life events.

Despite the above short-comings, I believe this study is useful for describing and defining the illness experience of hypothyroidism from the sufferer's perspective. An understanding of the subjective experience of a disease process can help doctors and other care-givers, including the families of the afflicted, achieve a more empathic understanding of their patients and loved ones. It can provide information for the sufferers themselves. Self-help groups are not available nor appealing to everyone, and the

self-help books that I have reviewed have again been written from the medical perspective of identifying and explaining symptoms and treatment, rather than explicating the social effects and coping mechanisms helpful in adjusting to the disease.

D. Possibilities for Future Research

A prospective longitudinal study of women with hypothyroidism might yield a somewhat different interpretation of their illness experience. People apply to problematic events whatever meanings or frames of reference are available to them at the time. Therefore, illness sufferers who are aware of their diagnosis may describe their early symptoms differently than those who are not. Interviewing each subject only once may have limited the description of the illness experience, and a longitudinal design might give a better indication of how sufferers adjust to their illness over time. Furthermore, a study that includes male sufferers of hypothyroidism would allow a comparison of the male and female experience of "seeking validation".

Perhaps the greatest benefit of small scale studies is their ability to define the questions and hypotheses to be tested in larger scale qualitative and quantitative research. This particular study could be expanded to include a wider sample or to initiate a large-scale survey of, for example, the membership of the Thyroid Foundation of

Canada. These studies could be used to further examine the "seeking validation" process, to include the experience of male sufferers of hypothyroidism, and to test hypotheses generated during this research, including the following:

1. Increasing public knowledge of hypothyroidism will decrease the tendency of sufferers to discount their symptoms and will shorten their pre-diagnosis trajectory.
2. Increasing public knowledge of hypothyroidism will decrease the stigma associated with its physical and psychological symptoms.
3. Increasing medical knowledge of the subjective experience of hypothyroidism will decrease the tendency for physicians to discount hypothyroid symptoms and will shorten the pre-diagnosis trajectory for hypothyroid patients.
4. Long pre-diagnosis trajectories of hypothyroidism will be associated with more social isolation, more marital and family disharmony, and less career advancement for the sufferer.
5. The longer the pre-diagnosis trajectory of hypothyroidism, the greater the number of different physicians consulted.
6. The longer the pre-diagnosis trajectory of hypothyroidism, the greater the tendency to consult alternative medical practitioners, such as chiropractors, religious healers, and homeopaths.

7. The longer the pre-diagnosis trajectory of hypothyroidism, the more problems will be encountered in adjusting to the disease and repairing damaged social relationships.
8. The longer the pre-diagnosis trajectory of hypothyroidism, the longer it will take for the sufferer to be regulated on a stable dose of thyroid hormone replacement.
9. Those sufferers who experience cyclic symptoms will have a longer illness trajectory, both prior to diagnosis and during the regulation of thyroid hormone replacement.
10. Those sufferers who experience cyclic symptoms will have more difficulty in adjusting to the illness.
11. Sufferers with Hashimoto's Disease are more likely to suffer cyclic exacerbations and remissions than those with other aetiologies for hypothyroidism.
12. When new symptoms appear or old ones reappear after thyroid hormone therapy has been established, they will once again tend to be discounted. With each episode of recurrence this tendency to discount symptoms will decrease.

E. Validity and Reliability

Standards of credibility must be applied to any research design, however the tests of validity[1] and

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1 Validity is "the extent to which the research findings represent reality" (Field and Morse, 1985:139).

reliability[2] applicable to quantitative research cannot be applied directly to qualitative studies. Proponents of the grounded theory method contend that, because the codes emerge from the data and are then constantly compared and contrasted with new data to check and refine emerging categories, grounded theory is inherently valid. Constant comparison of data from multiple subjects demonstrates empirically the variation within a category and multiple instances of a particular construct. In grounded theory, external validity increases as internal variety in the data increases. The greater the variation of data within categories, the greater the chance that the researcher has also discovered and examined any "negative cases", i.e., those that do not fit the appropriate category or proposition (Chenitz and Swanson, 1986).

When the object of a study is to uncover the subjects' subjective experiences then it is important to allow those subjects to tell their stories in their own words and so reveal "the way each person connects and interprets the events and experiences of [her] life" (McCurdy, 1990). Semi-structured interviews ensure that the researcher may guide the interview but at the same time limit the possibility of manipulating the data. When participants can tell their own stories, they emphasize that which is

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2 Reliability is "the measure of the extent to which random variation may have influenced the stability and consistency of the results" (Field and Morse, 1985:139).

important to them. In contrast, when the researcher asks more specific questions the data are more likely to exclude information that fails to conform to the researchers preconceived theoretical ideas about the research problem. By weaving verbatim accounts of the subject's stories into her report, the researcher demonstrates its validity. Graham suggests that "It is (or should be) a *sine qua non* of social research that informants have a story to tell. The integration of 'multiple biographies' into a survey design provides a simple and direct method through which they can tell it" (1984:120).

The extent to which the present research project represents the reality experienced by women suffering from hypothyroidism can be judged by how closely the study conforms to the above discussion of validity as applied to qualitative research. That the theory of "seeking validation" has been thoroughly grounded in the data is evident from the integration into the written theory of numerous verbatim quotations. Semi-structured interviews allowed the subjects to tell their own stories in their own words. The subjects' accounts of their illness experiences varied greatly in the severity and length of pre-diagnosis symptoms, as well as in their regulation on medication and their adjustments to the illness. By balancing the strategies used to achieve validation against the barriers that tend to prevent or delay validation, the theory is able to describe a wide range of hypothyroid illness experience.

In any event, the study appears to represent the reality experienced by the twelve women who participated in this project.

In addition, this theory conforms to Glaser's (1978) characteristics of grounded theory. It *fits* the data as the categories supporting the theory were gleaned from the data. The theory is *relevant*, relating directly to hypothyroidism, a particular chronic illness. The theory *works* in that it accounts for an important part of the experience of hypothyroidism. My belief is that the theory *can be modified* and extended without changing the essential process that it describes, for example, when it is later used to explore the experience of other sufferers of hypothyroidism and other chronic illnesses.

Reliability hinges upon a careful description and documentation of the research procedure. A major criticism of grounded theory has been its lack of replicability. According to Chenitz and Swanson (1986) the test of whether a grounded study can be replicated is not whether the same results could be obtained by a different researcher with different subjects but whether the theory can be applied to similar settings and to other types of problems over time, i.e., the theory has transcendence.

I believe the theory of "seeking validation" would emerge in other studies that explore hypothyroidism. In addition, the theory should apply to similar settings and other types of problems for which the sufferer needs

validation by others in order to achieve alleviation of her suffering. As such, the theory will stand Chenitz and Swanson's (1986) transcendence test of reliability. Possibilities for further research to test the theory are discussed in the next section.

F. Towards a General Theory of Validation

After developing a substantive theory the goal of grounded theory methodology is to test the theory in other situations to which it may apply. Although beyond the scope of this research project, I suspect that "seeking validation" is also inherent in the experience of many other chronic illnesses, especially other diseases manifest by vague subjective symptoms that are insidious in onset, easy to discount or blame on peripheral factors, and which may disappear and reappear periodically. Many other autoimmune illnesses conform to the above description including rheumatoid arthritis, pernicious anaemia, systemic lupus erythematosis, and multiple sclerosis. Such studies of validation for other chronic illnesses might benefit by expanding the data collection to include those who provide validation for her illness, e.g., families, co-workers, and care-givers, including the physician.

A general theory of validating also could apply to other situations beyond chronic illness. Procuring validation is also important for larger social movements in which an injustice, inequality, or change in circumstances

becomes recognized by one person or by a small group. When that small group needs to influence the people in power in order to eventually change the status quo, then the political process involved in gaining recognition for a cause may be likened to the process of "seeking validation". This invites applying the theory by looking at the process involved in achieving the social acceptance of labour unions, for example, or by looking at the contemporary but as yet incomplete processes of achieving gender and racial equality.

"Seeking validation" is perhaps similar to what Kuhn (1970) described when he wrote of a paradigm shift in science. When an individual researcher notices an aberration in the way normal science is conducted s/he would be at a stage similar to symptom recognition in Cell I. Furthermore, experimentally testing his/her theory is like the symptom attribution process in Cell I. S/He would then move into Cell II at the point of attempting to publish the research. Social validation is achieved as other scientists accept and replicate the results. When this theory becomes accepted as normal science, i.e., the new paradigm replaces the formerly accepted way of doing science, the scientist will have achieved complete validation in Cell III. Once again, Cell IV is the special case in which the scientist begins to doubt his/her own theory and the decision to modify it would "move" the scientist back into Cell I.

More research needs to be done to apply the theory of "seeking validation" to people with other illnesses and to people required by other circumstances to raise the consciousness of others. While the present study can not be relied on to predict the experience of everyone who suffers from hypothyroidism, the process of "seeking validation" does describe the experience of the twelve women who participated in the study and who believe they have experienced a degree of suffering that has not generally been recognized.

BIBLIOGRAPHY

Ablon, Joan. 1981. "Stigmatized Health Conditions." *Social Science and Medicine* 15B:5-9.

Advisory Committee on the Utilization of Medical Services. 1989. *An Agenda for Action*. Edmonton: Government of Alberta.

Antonovsky, Aaron. 1985. *Health, Stress and Coping*. San Francisco: Jossey-Bass Publishers.

_____. 1987. *Unraveling the Mystery of Health*. San Francisco: Jossey-Bass Publishers.

Armitage, Karen J., Lawrence J. Schneiderman, and Robert A. Bass. 1979. "Response of Physicians to Medical Complaints in Men and Women." *Journal of the American Medical Association* 241(20):2186-2187.

Asher, R. 1949. "Myxoedema Madness." *British Medical Journal* 2:555-562.

Avina, Robert L., and Lawrence J. Schneiderman. 1978. "Why Patients Choose Homeopathy." *Western Journal of Medicine* 128:366-369.

Bahemuka, M., and H. M. Hodkinson. 1975. "Screening for Hypothyroidism in Elderly Inpatients." *British Medical Journal* 2:601-603.

Barnes, Broda O., and Lawrence Galton. 1976. *Hypothyroidism: The Unsuspected Illness*. New York: Harper and Row Publishers.

Baron, Robert A., and Donn Byrne. 1984. *Social Psychology*. 4th ed. Boston: Allyn and Bacon.

Barrett, Michele, and Helen Roberts. 1978. "Doctors and Their Patients: The Social Control of Women in General Practise." Pp. 41-52, in *Women, Sexuality and Social Control* edited by Carol Smart and Barry Smart. London: Routledge and Kegan Paul.

Bayliss, R. I. S. 1982. *Thyroid Disease: The Facts*. Oxford: Oxford University Press.

Beall, Gildon N., and David H. Soloman. 1973. "Immunologic Features of Thyroid Disease." *Post-Graduate Medicine* 54(5): 181-189.

Bell, G. M., W. T. A. Todd, J. C. Forfar, C. Martyn, C. G. Wathen, S. Gow, R. Reimersma, and A. D. Toft. 1985. "End-Organ Responses to Thyroxine Therapy in Subclinical Hypothyroidism." *Clinical Endochrinology* 22:83-89.

Benoliel, Jeanne Quint. 1975. "Childhood Diabetes: The Commonplace in Living Becomes Uncommon." Pp. 89-98 in *Chronic Illness and the Quality of Life*, edited by Anselm Strauss. St. Louis: C. V. Mosby Company.

Birenbaum, Arnold. 1981. *Health Care and Society*. Montclair, New Jersey: Allanheld, Osmun and Company.

Canadian Pharmaceutical Association. 1988. *Compendium of Pharmaceuticals and Specialities* 23rd ed.

Canadian Task Force on the Periodic Health Examination. 1990. "Periodic Health Examination, 1990 Update: 1. Early Detection of Hyperthyroidism and Hypothyroidism in Adults and screening of Newborns for Congenital Hypothyroidism." *Canadian Medical Association Journal* 142(9):955-961.

Charmaz, Kathy. 1983a. "The Grounded Theory Method: An Explication and Interpretation." Pp.109-126 in *Contemporary Field Research*, edited by Robert M. Emerson. Boston: Little, Brown and Co.

_____. 1983b. "Loss of Self: A Fundamental Form of Suffering in the Chronically Ill." *Sociology of Health and Illness* 5(2):168-195.

_____. 1987. "Struggling for a Self: Identity Levels of the Chronically Ill." *The Sociology of Health Care* 6:283-321.

Chenitz, W. Carole, and Janice M. Swanson. 1986. *From Practise to Grounded Theory: Qualitative Research in Nursing*. Menlo Park, California: Addison-Wesley Publishing.

Cobb, Ann Kuckelman, and Edna Hamera. 1986. "Illness Experience in a Chronic Disease--ALS." *Social Science and Medicine* 23(7):641-650.

Cockerham, William C. 1986. *Medical Sociology* 3rd ed. Englewood Cliffs, New Jersey: Prentice-Hall.

Cohen, Kenneth L., and Mary E. Swigar. 1979. "Thyroid Function Screening in Psychiatric Patients." *Journal of the American Medical Association* 242(3):254-257.

College of Physicians and Surgeons of Alberta. 1989. "Thyroid Testing." *Report from Council*. Winter:32-33.

Conrad, Peter 1987. "The Experience of Illness: Recent and New Directions." *Research in the Sociology of Health Care* 6:1-31.

Cooper, David S., Rachelle Halpern, Lawrence C. Wood, Ann A. Levin, and Chester Ridgway. 1984. "L-Thyroxine Therapy in Subclinical Hypothyroidism". *Annals of Internal Medicine* 101:18-24.

Corbin, Juliet M., and Anselm L. Strauss, 1984. "Collaboration: Couples Working Together to Manage Chronic Illness." *The Journal of Nursing Scholarship* 16(4):109-115.

Coulter, Harris L. 1984. "Homeopathy." Pp. 57-79, in *Alternative Medicines* edited by J. Warren Salmon. New York: Tavistock Publications.

Cousins, Norman. 1979. *Anatomy of An Illness*. New York: W. W. Norton and Company.

Craib, Ian. 1985. *Modern Social Theory*. Brighton, England: Wheatsheaf Books Ltd.

Cronin, A. J. 1937. *The Citadel*. Boston: Little, Brown and Company.

Dahlberg, Per Anders, and Rolf Jansson. 1983. "Different Aetiologies in Post-Partum Thyroiditis?." *Acta Endocrinologica* 104:195-200.

DeGroot, Leslie J. 1973. "The Thyroid." Pp. 1703-1733 in *Textbook of Medicine* Vol. II, edited by Paul B. Beeson, and Walsh McDermott. Philadelphia: W. B. Saunders Company.

Dungal, Leifur. 1978. "Physicians's Responses to Patients: A Study of Factors Involved in the Office Interview." *The Journal of Family Practise* 6(5):1065-1073.

Eisenberg, Leon. 1977a. "Disease and Illness: Distinctions Between Professional and Popular Ideas of Sickness." *Culture, Medicine and Psychiatry* 1:9-23.

_____. 1977b. "The Search for Care." *Deadelus* 106:235-246.

Ellinwood, J. Christopher, and Gregory J O'Shanick. 1983. "Drs. Ellinwood and O'Shanick Reply." *American Journal of Psychiatry* 140(4):512.

Evered, D. C., B. J. Ormston, P. A. Smith, R. Hall, and T. Bird. 1973. "Grades of Hypothyroidism." *British Medical Journal* 1:657-662.

Evered, David C. 1976. *Diseases of the Thyroid*. Tunbridge Wells: Pitman Medical Publishing Company.

Fabriga, Horacio. 1973. "Toward a Model of Illness Behavior." *Medical Care* 11(6):470-484.

Fagerhaugh, Shizuko. 1975. "Getting Around With Emphysema." Pp. 99-107 in *Chronic Illness and the Quality of Life*, edited by Anselm Strauss. St. Louis: C. V. Mosby Company.

Falkenberg, Melcher, Bertil Kagedal, and Anders Norr. 1983. "Screening of an Elderly Female Population for Hypo- and Hyperthyroidism by Use of a Thyroid Hormone Panel." *Acta Medical Scandinavica* 214:361-365.

Farquharson, Andy. 1981. "Self-Help Groups: A Health Resource," in *Health and Canadian Society* 1st ed., edited by David Coburn, Carl D'Arcy, Peter New, and George Torrance. Markham, Ontario: Fitzhenry and Whiteside.

Festinger, Leon. 1954. "A Theory of Social Comparison Processes." *Human Relations* 7:117-140.

Field, Peggy Anne, and Janice M. Morse. 1985. *Nursing Research: The Application of Qualitative Approaches*. Rockville, Maryland: Aspen Publishers Inc.

Fielding, Nigel G., and Jane L. Fielding. 1986. *Linking Data*. Beverly Hills: Sage Publications, Inc.

Finch, Janet. 1984. " 'It's Great to Have Someone to Talk To': The Ethics and Politics of Interviewing Women." Pp. 70-87 in *Social Researching: Politics, Probelms, Practise*, edited by Colin Bell and Helen Roberts. London: Routledge and Kegan Paul.

Fisher, D. A., T. H. Oddie, D. E. Johnson, and J. C. Nelson. 1975. "The Diagnosis of Hashimoto's Thyroiditis." *Journal of Clinical Endocrinology and Metabolism* 40:795-801.

Flaherty, Robert J. 1984. "Postpartum Thyroiditis." *American Family Physician* 29(2):195-197.

Fowler, Edson F. 1960. "The Changing Incidence and Treatment of Thyroid Disease." *Archives of Surgery* 81:733-740.

Freidson, Eliot. 1961. *Patients' Views of Medical Practise*. New York: Russell Sage Foundation.

_____. 1970. *Profession of Medicine*. New York: Dodd, Mead, cited in Cockerham, William C. *Medical Sociology* 3rd ed. Englewood Cliffs: Prentice-Hall.

Furszyfer, Jacob, Leonard T. Kurland, Lewis B. Woolner, Lila R. Elveback, and William M. McConahey. 1970. "Hashimoto's Thyroiditis in Olmsted County, Minnesota, 1935 Through 1967." *Mayo Clinic Proceedings* 45:586-596.

Geiger, H. Jack. 1975. "The Causes of Dehumanization in Health Care and Prospects for Humanization." Pp. 11-36, in *Humanizing Health Care*, edited by Jan Howard and Anselm Strauss. New York: John Wiley and Sons.

Ginsberg, Susannah M., and George W. Brown. 1982. "No Time for Depression: A Study of Help-Seeking Among Mothers of Preschool Children." Pp. 87-114, in *Symptoms, Illness Behavior and Help-Seeking*, edited by David Mechanic. New York: Neale Watson Academic Publications.

Glaser, Barney G. 1978. *Theoretical Sensitivity*. Mill Valley, California: The Sociology Press.

Glaser, Barney G., and Anselm L. Strauss. 1967. *The Discovery of Grounded Theory*. Chicago: Aldine Publishing Company.

Glaser, Barney G., and Anselm L. Strauss. 1968. *Time for Dying*. Chicago: Aldine Publishing Company.

Goffman, Erving. 1959. *The Presentation of Self in Everyday Life*. Garden City, New York: Doubleday Anchor Books.

_____. 1963. *Stigma*. Englewood Cliffs: Prentice-Hall, Inc.

Gold, Mark S., A. L. C. Pottash, and Irl Extein. 1981. "Hypothyroidism and Depression: Evidence from Complete Thyroid Function Evaluation." *Journal of the American Medical Association* 245(19):1919-1922.

Gold, Mark S., and H. Rowland Pearsall. 1983. Hypothyroidism--or is it Depression?." *Psychosomatics* 24(7):646-656.

Gordin, A.; P. Saarinen; R. Pelkonen; and B.-A. Lamberg. 1974. "Serum Thyrotrophin and the Response to Thyrotrophin Releasing Hormone in Symptomless Autoimmune Thyroiditis and in Borderline and Ovent Hypothyroidism." *Acta Endocrinologica* 75:274-285.

Gordin, A., and B.-A. Lamberg. 1981. "Spontaneous Hypothyroidism in Symptomless Autoimmune Thyroiditis: A Long-Term Follow-up Study." *Clinical Endocrinology* 15:537-543.

Gossain, Ved V., David R. Rovner, and Charles E. Rhodes. 1983. "Recurrent Transient Hyperthyroidism and Hypothyroidism Associated with Pregnancy." *Southern Medical Journal* 76(6):808-810.

Graham, Hilary. 1984. "Surveying through Stories." Pp. 104-124, in *Social Researching: Politics, Problems, Practise*, edited by Colin Bell and Helen Roberts. London: Routledge and Kegan Paul.

Gussow, Zachary, and George S. Tracy. 1976. "The Role of Self-Help Clubs in Adaptation to Chronic Illness and Disability." *Social Science and Medicine* 10:407-414.

Haggerty, John J.; Dwight L. Evans, and Arthur J. Prange. 1986. "Organic Brain Syndrome Associated with Marginal Hypothyroidism." *American Journal of Psychiatry* 143(6):785-786.

Hall, Richard C. W., Michael K. Popkin, Richard DeVaul, Hall, Anne K.; Earl R. Gardner, and Thomas P. Beresford. 1982. "Psychiatric Manifestations of Hashimoto's Thyroiditis." *Psychomatics* 23(4):337-342.

Hall, Richard C. W. 1983. "Psychiatric Effects of Thyroid Hormone Disturbance." *Psychosomatics* 24(1):7-18.

Health and Welfare Canada. 1981. *The Health of Canadians--Report of the Canada Health Survey*. Ottawa: Statistics Canada.

Holden, Constance. 1978. "Holistic Health Concepts Gaining Momentum." *Science* 200:1029.

Howard, Jan. 1975. "Humanization and Dehumanization of Health Care: A Conceptual View." Pp. 57-102 in *Humanizing Health Care*, edited by Jan Howard and Anselm Strauss. New York: John Wiley and Sons.

Hudacin, Jean. 1985. "A Survey of Thyroid Patients Who Are Members of the Thyroid Foundation of Canada Including Characteristics of the Patient, Associated Disease and Impact of Thyroid Disease on Lifestyle." M.Sc. Thesis. Queen's University.

Hutchinson, Sally. 1986. "Grounded Theory: The Method." Pp. 111-130 in *Nursing Research: A Qualitative Perspective*, edited by Patricia L. Munhall and Carolyn Oiler. Norwalk, Conn.: Appleton-Century-Crofts.

"Hypothyroidism: A Treacherous Masquerader." *Acute Care Medicine* May 1984:24-26.

Jaffiol, Claude; Line Baldet, Andre Pages, and Jacques Clot. 1983. "Graves' Disease Progressing to Hashimoto's Thyroiditis." *Journal of the American Medical Association* 250(5):644-645.

Janis, Irving L. 1967. "Effects of Fear Arousal on Attitude Change: Recent Developments in Theory and Experimental Research." Pp. 166-224 in *Advances in Experimental Social Psychology*. Vol. 3, edited by L. Berkowitz. New York: Academic Press.

_____. 1975. "Preventing Dehumanization: Commentary on Howard Leventhal's Information-Processing Model." Pp. 163-174, in *Humanizing Health Care*, edited by Jan Howard and Anselm Strauss. New York: John Wiley and Sons.

Janoff-Bulman, Ronnie, and Irene Hanson Frieze. 1983. "A Theoretical Perspective for Understanding Reactions to Victimization." *Journal of Social Issues* 39(2):1-117.

Janoff-Bulman, Ronnie, and Christine Timko. 1987. "Coping with Traumatic Life Events: The Role of Denial in Light of People's Assumptive Worlds." Pp. 135-159, in *Coping With Negative Life Events*, edited by C. R. Snyder and C. E. Ford. New York: Plenum Press.

Jansson, Rolf; Per Anders Dahlberg, and Anders Karlsson. 1984. "Postpartum Thyroid Dysfunction." *Scandinavian Journal of Clinical Laboratory Investigation* 44:371-375.

Johnson, Shirley M., and Margot E. Kurtz. 1990. "Implications for Health of Stereotypic Responses." *Humane Medicine* 6(2):120-127.

Kandel, Denise B., Mark Davies, and Victoria H. Reveis. 1985. "The Stressfulness of Daily Social Roles for Women: Marital, Occupational and Household Roles." *Journal of Health and Social Behavior* 26:64-78.

Kennedy, Donald A. 1975. "Adaptation to More Humanizing Forms of Health Care." Pp. 189-214, in *Humanizing Health Care*, edited by Jan Howard and Anselm Strauss. New York: John Wiley and Sons.

Kirk, Jerome, and Marc L. Miller. 1986. *Reliability and Validity in Qualitative Research*. Beverly Hills: Sage Publications.

Klein, Irwin, and Gerald S. Levey. 1984. "Unusual Manifestations of Hypothyroidism." *Archives of Internal Medicine* 144:123-128.

Kleinman, Arthur. 1978. "The Failure of Western Medicine." *Human Nature* November:63-68.

Langer, Stephen E., and James F. Scheer. 1984. *Solved: The Riddle of Illness*. New Canaan, Connecticut: Keats Publishing.

Larson, Magali Sarfatti. 1977. *The Rise of Professionalism: A Sociological Analysis*. Berkely: University of California Press.

Lazarsfeld, P. F., and A. Barton. 1971. "Qualitative Measurement in the Social Science." Pp. 140-160 in *Research Methods: Issues and Insights*, edited by Billy J. Franklin and Harold W. Osborne. Belmont, California: Wadsworth Publishing Co. Inc.

Lefton, Mark. 1984. "Chronic Disease and Applied Sociology: An Essay in Personalized Sociology." *Sociological Inquiry* 54(4):466-476.

Leigh, Hoyle, and Morton F. Reiser. 1985. *The Patient* 2nd ed. New York: Plenum Medical Book Company.

Leventhal, Howard. 1975. "The Consequences of Depersonalization During Illness and Treatment." Pp. 119-161, in *Humanizing Health Care*, edited by Jan Howard and Anselm Strauss. New York: John Wiley and Sons.

Leventhal, Howard, David R. Nerenz, and Andrea Straus. 1982. "Self-Regulation and the Mechanisms for Symptom Appraisal." Pp. 55-86, in *Symptoms, Illness Behavior and Help-Seeking*, edited by David Mechanic. New York: Neale Watson Academic Publications.

Levine, Sol. 1975. "A Sociologist's Perspective." Pp. 285-292 in *Humanizing Health Care*, edited by Jan Howard and Anselm Strauss. New York: John Wiley and Sons.

Lewis, Kathleen. 1983. "Grief in Chronic Illness and Disability." *Journal of Rehabilitation* July/Aug:8-11.

Leznoff, Arthur, Robert G. Josse, Judah Denburg, and Jerry Dolovich. 1983. "Association of Chronic Urticaria and Angioedema with Thyroid Autoimmunity." *Archives of Dermatology* 119:636-640.

Lofland, John. 1971. *Analysing Social Settings: A Guide to Qualitative Observation and Analysis*. Belmont, California: Wadsworth Publishing Co.

Loosen, Peter T., and Alan Tipermas. 1983. "Thyroid Hormones in Manic-Depressive Disorders." *American Journal of Psychiatry* 140(4):511-512.

Macksood, William, Richard L. Rapport, and Frank Hodges. 1961. "The Increasing Incidence of Hashimoto's Disease." *Archives of Surgery* 83:384-387.

Markus, H., and R. B. Zyjonc. 1985. "The Cognitive Perspective in Social Psychology." Pp. 137-231 in *The Handbood of Social Psychology*. Vol. 1, edited by G. Lindzey and E. Aronson.

Masi, Alfonse T. 1965. "Hashimoto's Disease: An Epidemiological Study Based on a Community-Wide Hospital Survey." *Journal of Chronic Disease* 18:35-57.

Mattes, Jeffery A. 1986. "Psychopharmacology of Temper Outbursts." *The Journal of Nervous and Mental Disease* 174(8):464-470.

McConahey, William M. 1975. "Hypothyroidism." *Hospital Medicine* April, reproduced with permission by Kingston: The Thyroid Foundation of Canada.

McCracken, Grant. 1988. *The Long Interview*. Qualitative Research Methods. Vol. 13. Beverly Hills: Sage Publications.

McCurdy, David B. 1990. "Respecting Autonomy by Respecting Persons: Taking the Patient's Story Seriously." *Humane Medicine* 6(2):107-112.

McGuire, Meredith B. 1987a. "Ritual, Symbolism and Healing.", *Social Compass* 24(4):365-379.

_____. 1987b. *Religion: The Social Content*, 2nd ed. Belmont, California: Wadsworth Publishing Company.

_____. 1989. "Healing Rituals Hit the Suburbs." *Psychology Today* January/February:57-64.

Mechanic, David. 1972. "Social Psychological Factors Affecting the Presentation of Bodily Complaints." *New England Journal of Medicine* 286(21):1132-1139.

_____. 1975. "Introduction." Pp. 1-5 in *Humanizing Health Care*, edited by Jan Howard and Anselm Strauss. New York: John Wiley and Sons.

_____. 1978a. *Medical Sociology* 2nd ed. New York: The Free Press.

_____. 1978b. "Sex, Illness, Illness Behavior and the Use of Health Services." *Social Science and Medicine* 12(B):207-214.

Miles, Mathew B., and A. Michael. Huberman. 1984. *Qualitive Data Analysis: A Source Book of New Methods*. Beverly Hills: Sage Publications.

Miller, D. T., and M. Ross. 1975. "Self-serving Biases in the Attribution of Causality: Fact or Fiction?" *Psychological Bulletin* 82:213-225, cited in Robert A. Baron, and Donn Byrne. 1984. *Social Psychology* 4th ed. Boston: Allyn and Bacon.

Miller, Judith Fitzgerald. 1983. *Coping With Chronic Illness: Overcoming Powerlessness*. Philadelphia: F. A. Davis Company.

Mishel, Merle H. 1981. "The Measurement of Uncertainty in Illness." *Nursing Research* 30(5):258-263.

Nolen, James P., Nancy J Tarsa, and Gene DiBenedetto. 1985. "Case-Finding for Unsuspected Thyroid Disease: Costs and Benefits." *American Journal of Clinical Pathology* 83(3):346-355.

Norton, R. W. 1975. "Measurement of Ambiguity Tolerance." *Journal of Personality Assessment* 39:607-619, cited in Merle H. Mishel. 1981. "The Measurement of Uncertainty in Illness." *Nursing Research* 30(5):258-263.

Nusynowitz, Martin L., and Col. Robert L. Young. 1979. "Thyroid Dysfunction in the Ailing, Aging and Aberrant." *Journal of the American Medical Association* 242(3):275-276.

Nystrom, E., K. Caidahl, G. Fager, C. Wikkelso, P.-A. Lundberg, and G. Lindstedt. 1988. "A Double-Blind Cross-over 12 Month Study of L-Thyroixine Treatment of women with 'Subclinical' Hypothyroidism." *Clinical Endocrinology* 29:63-76.

Nystrom, Ernst, Calle Bengtsson, Olle Linquist, Henry Noppa, Goran Lindstedt, and Per-Arne. Lundberg. 1981. "Thyroid Disease and High Concentration of Serum Thyrotropin in a Population Sample of Women." *Acta Medica Scandinavica* 210:39-46.

Parker, Gordon, and Hilary. Tupling. 1977. "Consumer Evaluation of Natural Therapists and General Practitioners." *Medical Journal of Australia* 1:619-622.

Parse, Rosemarie Rizzo, A. Barbara Coyne, and Mary Jane Smith. 1985. *Nursing Research: Qualitative Methods*. Bowie, Maryland: Brady Communications: A Prentice-Hall Publishing Company.

Parsons, Talcott. 1951. *The Social System*. New York: The Free Press.

Paulley, J. W. 1983. "Patholgical Mourning: A Key Factor in the Psychopathogenesis of Auto-immune Disorders." *Psychotherapy and Psychosomatics* 41:181-190.

Pirie, Marion. 1988. "Women and the Illness Role: Rethinking Feminist Theory." *Canadian Review of Sociology and Anthropology* 25(4)628-648.

Pratt, Lois, Arthur Seligman, and George Reader. 1957. "Physicians' Views on the Level of Medical Information Among Patients." *American Journal of Public Health* 47:1277-1283.

Quint, Jeanne C. 1967. "The Case for Theories Generated From Empirical Data." *Nursing Research* 16(2):109-114.

Reisine, Susan T., Carol Goodenow, and Kathleen E. Grady. 1987. "The Impact of Rheumatoid Arthritis on the Homemaker." *Social Science and Medicine* 25(1):89-95.

Riddervold, Fridtjov. 1983. "Natural Course of Intermittent Chronic Autoimmune Thyroiditis." *Acta Endocrinologica* 102:46-48.

Rief, Laura. 1975. "Ulcerative Colitis: Strategies for Managing Life." Pp. 81-98 in *Chronic Illness and the Quality of Life*, edited by Anselm Strauss. St. Louis: C. V. Mosby Company.

Rimm, Alfred A., Linda H. Werner, Barbara van Yserloo, and Ronald A. Berstein. 1975. "Relationship of Obesity and Disease in 73,532 Weight-Conscious Women." *Public Health Reports* 90(1):44-51.

Rippere, Vicky. 1983. "Biochemical Victims: False Negative Diagnosis through Overreliance on Laboratory Results...A Personal Report." *Medical Hypotheses* 10:113-130.

Roberts, Helen. 1981. "Women and Their Doctors: Power and Powerlessness in the Research Process." Pp. 7-29 in *Doing Feminist Research*, edited by Helen Roberts. London: Routledge and Kegan Paul.

Roberts, Helen. 1985. *The Patient Patients: Women and Their Doctors*. London: Pandora Press.

Roitt, I. M. Deborah Doniach, P. N. Campbell, and R. Vaughan Hudson. 1956. "Auto-antibodies in Hashimoto's Disease (Lymphadenoid Goitre)." *The Lancet* 2:820-821.

Rosenhan, D. L. 1973. "On Being Sane in Insane Places." *Science* 179:250-258.

Rosenthal, Mark J., William C. Hunt, Philip J. Garry, and James S. Goodwin. 1987. "Thyroid Failure in the Elderly: Microsomal Antibodies as Discriminant for Therapy." *Journal of the American Medical Association* 258(2):209-213.

Sachar, Edward, J., Gregory Asnis, Uriel Halbreich, R. Swami Nathan, and Frieda Halpern. 1980. "Recent Studies in the Neuroendocrinology of Major Depressive Disorders." *Psychiatric Clinics of North America* 3(2):313-326.

Safer, Martin A., Quincy J. Tharps, Thomas C. Jackson, and Howard Leventhal. 1979. "Determinants of Three Stages of Delay in Seeking Care at a Medical Clinic." *Medical Care* 17(1):11-29.

Sawin, Clark, T., Deepak Chopra, Fereidoun Azizi, Jo Ellen Mannix, and Pamela Bacharach. 1979. "The Aging Thyroid." *Journal of the American Medical Association* 242(3):247-250.

Schachter, Stanley. 1964. "The Interaction of Cognitive and Physiological Determinants of Emotional State." Pp. 49-80 in *Advances in Experimental Social Psychology* Vol 1, edited by Leonard Berkowitz. New York: Academic Press.

Schachter, Stanley, and Jerome E. Singer. 1962. "Cognitive, Social and Physiological Determinants of Emotional State." *Psychological Review* 69(5):379-399.

Schatzman, Leonard and Anselm L. Strauss. 1973. *Field Research: Strategies for a Natural Sociology*. Englewood Cliffs, New Jersey: Prentice-Hall.

Schneider, Joseph W. and Peter Conrad. 1983. *Having Epilepsy: The Experience and Control of Illness*. Philadelphia: Temple University Press.

Seeman, Melvin, and Teresa Seeman. "Health Behavior and Personal Autonomy: A Longitudinal Study of the Sense of Control in Illness." *Journal of Health and Social Behavior* 24(June):144-160.

Seidel, John V., Rolf Kjolseth, and Elaine Seymore. 1988. *The Ethnograph: A User's Guide (Version 3.0)*. Littleton, Colorado: Qualis Research Associates.

Shaw, Eric, James Halper, Peter E. Yi, and Stuart Asch. 1985. "Diagnosis of Myzedema Madness." *American Journal of Psychiatry* 142(5):655.

Singer, Eleanor. 1974. "Premature Social Aging: The Social-Psychological Consequences of A Chronic Disease." *Social Science and Medicine* 8:143-151.

Solomon, David H. 1986. "Clinical Examination of the Thyroid." Pp. 19-34 in *The Thyroid Gland*, edited by Lester van Middlesworth. Chicago: Yearbook Medical Publishers.

Stein, Murray B., and Thomas W. Uhde. 1989. "Autoimmune Thyroiditis and Panic Disorder." *American Journal of Psychiatry* 146(2):259-260.

Stern, Phyllis Noerager. 1987. "Grounded Theory Methodology: Its Uses and Processes." Pp. 79-87 in *Nursing Science Methods: A Reader*, edited by Susan R. Gortner. San Francisco: Regents, University of California.

Stimson, Gerry V. 1976. "General Practitioners: Trouble and Types of Patients," in *The Sociology of the National Health Service*, edited by Margaret Stacy. Sociological Review Monograph #22. University of Keele, cited in Roberts, Helen. 1985. *The Patient Patients: Women and Their Doctors*. London: Pandora Press.

Stimson, Gerry, and Barbara Webb. 1975. *Going To See The Doctor*. London: Routledge and Kegan Paul.

Strauss, Anselm. 1970. "Discovering New Theory from Previous Theory." Pp. 46-53, in *Human Nature and Collective Behavior*, edited by Tamotsu Shibutani. Englewood Cliffs, new Jersey: Prentice-Hall.

_____. 1973. "Chronic Illness." *Society* 10(6):33-39.

_____. 1975. *Chronic Illness and the Quality of Life*. St. Louis: C. V. Mosby Company.

_____. 1987. *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press.

Suchman, Edward A. 1965. "Stages of Illness and Medical Care." *Journal of Health and Human Behavior* 6:114-128.

Suszek, Barbara. 1975. "Chronic Renal Failure and the Problem of Funding." Pp. 108-118 in *Chronic Illness and the Quality of Life*, edited by Anselm Strauss. St. Louis: C. V. Mosby Company.

Swanson-Kauffman, Kristen M. 1986. "A Combined Qualitative Methodology for Nursing Research." *Advances in Nursing Science* 8:58-69.

Taylor, Rosemary C. R. 1984. "Alternative Medicines and the Medical Encounter in Britain and the United States." Pp. 191-228 in *Alternative Medicines*, edited by J. Warren Salmon. New York: Tavistock Publications.

The Compact Edition of the Oxford English Dictionary. 1971. New York: Oxford University Press.

Tibaldi, J., and U. S. Barzel. 1985. "Thyroid Supplementation: Method for the Prevention of Clinical Hypothyroidism." *The American Journal of Medicine* 79:241-244.

Todd, Alexandra Dundas. 1989. *Intimate Adversaries: Cultural Conflict Between Doctors and Women Patients*. Philadelphia: University of Pennsylvania Press.

Trypuc, Joann M. 1988. "Women's Health." Pp. 154-166 in *Sociology of Health Care in Canada*, edited by B. Singh Bolaria and Harley D. Dickinson. Toronto: Harcourt, Brace, Jovanovich.

Tunbridge, W. M. G., D. C. Evered, R. Hall, D. Appleton, M. Brewis, F. Clark, J. Grimley Evans, E. Young, T. Bird, and P. A. Smith. 1977. "The Spectrum of Thyroid Disease in a Community: The Whickham Survey." *Clinical Endocrinology* 7:481-493.

Twaddle, Andrew C., and Richard M. Hessler. 1987. *A Sociology of Health* 2nd ed. New York: Macmillan Publishing Company.

Verbrugge, Lois M. 1983. "Multiple Roles and Physical Health of Women and Men." *Journal of Health and Social Behavior* 24(March):16-30.

_____. 1985. "Gender and Health: An Update on Hypotheses and Evidence." *Journal of Health and Social Behavior* 26(Sept.):156-182.

Waitzkin, Howard. 1985. "Information Giving in Medical Care." *Journal of Health and Social Behavior* 26:81-101.

Wallen, Jacqueline, Howard Waitzkin, and John D. Stoeckle. 1979. "Physician Stereotypes About Female Health and Illness: A Study of Patient's Sex and the Informative Process During Medical Interviews." *Women and Health*. 4(Summer):135-146.

Walsh, B. Timothy. 1980. "The Endocrinology of Anorexia Nervosa." *Psychiatric Clinics of North America* 3(2):299-311.

Weiner, Carolyn L. 1975. "The Burden of Rheumatoid Arthritis." Pp. 71-80, in *Chronic Illness and the Quality of Life*, edited by Anselm Strauss. St. Louis: C. V. Mosby and Company.

Wilson, William H., and James W. Jefferson. 1985. "Thyroid Disease, Behavior and Psychopharmacology." *Psychosomatics* 26(6):481-492.

Yin, Robert K. 1984. *Case Study Research: Design and Methods*. Beverly Hills: Sage Publications.

Young, Donald G. 1988. "Physicians Can Reduce Costs." *Alberta Doctor's Digest* January/February:11

Zola, Irving Kenneth. 1973. "Pathways to the Doctor--From Person to Patient." *Social Science and Medicine* 7:677-689.

APPENDIX A SPEECH TO RECRUIT SAMPLE FOR MASTER'S RESEARCH

THYROID FOUNDATION OF CANADA

EDMONTON CHAPTER MEETING MAY 17, 1989

GOOD EVENING.

My name is Jane Milliken. I am a master's student in sociology at the University of Alberta. My background in nursing, although I didn't work for twelve years when my four children were small, has led to an interest in medical sociology. Years ago, just after we graduated in nursing, my room-mate developed hypothyroidism. Tonight I have come to your meeting to ask for your help with my research into hypothyroidism.

Everyone here has an interest in abnormalities of the thyroid gland. You, or someone close to you, is (or has been) ill with a thyroid disease. For sociologists there is a difference between a disease and an illness. A disease is a medical phenomenon defined by an identifiable group of physical signs and symptoms, while an illness is defined through the perception, behavior and individual experience of the sufferer. While the two usually occur together, a particular individual may feel ill in the absence of an identifiable disease, yet another person may have the biological changes characteristic of a disease without actually feeling ill.

I am particularly interested in hypothyroidism as an illness experience, yet most of what I have read to date describes the disease, that is, the causes, clinical symptoms, diagnosis and treatment. I was left to speculate and guess what it may mean to the person whose disease develops gradually, whose diagnosis is uncertain, whose physical appearance may change, who is constantly tired, weak, perhaps irritable or depressed (OR ALL OF THE ABOVE) and whose recovery can be slow and frustrating.

I hope to find out what hypothyroidism **does** mean to the person who experiences the symptoms, the uncertainty, the frustrations, the ups and downs. It is your perspective, YOUR STORY, that I want to hear, and how you have been able to deal in your everyday life with the "curves" thrown at you by this disease, --both the big crises and the little problems. Do many people deal with them in the same way or in various ways? Maybe your disease-course has been without any real problems. If so, I'd like to know. I suspect that the need for an organization such as this suggests a desire to share experiences and, in so doing, help each other through the rough parts.

My intention is to interview up to twenty women for approximately one hour each, starting in August and continuing through September, possibly October. The interviews will be arranged at your convenience, hopefully in your own home where you will be most at ease -- although,

if you would rather, I can make other arrangements. I would like to tape the interviews, but the typed transcripts will be numbered rather than named. I can assure you of complete confidentiality and that no actual names or identifying features will appear in my thesis.

Research, such as this, can, I think, help public health and other care-givers, including families, achieve a more empathetic understanding of their patients and loved ones. It can provide information for the sufferers themselves. Not everyone with hypothyroidism has access to a self-help organization. Finally, small scale studies can help define the questions for further research in an area.

When my thesis is completed, I will be happy to come to one of your meetings to tell you about it, if you wish. Does anyone have any questions?

I would like to circulate these forms around the meeting so that anyone who is able and would like to participate can give me your name and telephone number, so that I can contact you to arrange a time to talk with you. Once again, no one will see this list except myself, and you are perfectly free to change your mind about taking part at any time.

If you would like to talk to me personally about this project, I will be staying after the meeting for as long as

you wish. I can also be contacted during the day through the Department of Sociology at the U. of A. --492-5234.

Thank you very much.

APPENDIX B REPLY FORM FOR VOLUNTEERS FOR THE STUDY

HYPOTHYROIDISM RESEARCH PROJECT

(Mrs.) Jane Milliken Masters Student

University of Alberta
Department of Sociology 492-5234

[ ] I will participate in this research project.

[ ] I will not participate in this research project.

NAME: _____

PHONE NUMBER: _____

HYPOTHYROIDISM RESEARCH PROJECT

(Mrs.) Jane Milliken Masters Student

University of Alberta
Department of Sociology 492-5234

[ ] I will participate in this research project.

[ ] I will not participate in this research project.

NAME: _____

PHONE NUMBER: _____

APPENDIX C LETTER FOR SNOWBALLING OF SAMPLE

Hello,

Recently a mutual acquaintance told me that he or she knew someone who had been diagnosed as having hypothyroidism. This person did not give me your name. Instead, I requested that he or she send you this letter asking for your help with my research into the life experiences of people with hypothyroidism.

I am a former nurse, presently studying medical sociology at the University of Alberta and this study will form the basis of my thesis for a Master of Arts degree. While most research on hypothyroidism has focussed on the causes, symptoms and treatment of the disease, I am particularly interested in how this illness affects the everyday life of the people who have it. I would like to interview you (confidentially, of course) for about an hour, to learn more about the social and personal experiences, problems and adjustments people with hypothyroidism face in our society. The results of research such as this can help others with hypothyroidism, and help their families and care-givers achieve a more empathetic understanding of what their loved ones and patients are going through.

If you agree to be interviewed, I can assure you of complete confidentiality and that no actual names of identifying features will appear in my thesis. For the purpose of accuracy I intend to tape-record the interview but, when typed, the transcript will be numbered rather than identified by name. We could meet in your own home or, alternatively, I will arrange a room at the university.

If you agree to participate, please write your name and telephone number on the enclosed form and return it to me. I will then call you to arrange a time for the interview. If you have any questions you wish to ask before agreeing to participate, please leave a message for me at the Department of Sociology, University of Alberta, between 8:00 a.m. and 4:30 p.m., Monday to Friday. The telephone number is 492-5234. I will return your call promptly.

Again, as I don't know who you are, the person who knows you has agreed to forward this letter to you. Thank you for your consideration. I hope to be hearing from you.

Sincerely,

(Mrs.) Jane Milliken, B.Sc.N.

APPENDIX D MAILED REPLY FORM FOR VOLUNTEERS

Please return this form in the self-addressed, stamped envelope provided.

I would like to participate in the study on hypothyroidism conducted by Mrs. Jane Milliken.

Name: _____

Telephone number: _____

APPENDIX E INTERVIEW SCHEDULE

Face Sheet Data:

INTERVIEW NUMBER_____

DATE OF INTERVIEW_____

BIRTHDATE_____

AGE AT DIAGNOSIS_____

MARITAL STATUS_____

OCCUPATION_____

OCCUPATION PRIOR TO ILLNESS_____

SPOUSE'S OCCUPATION_____

AGE AND GENDER OF CHILDREN_____

_____

_____

_____

SIGNIFICANT FEATURES OF INTERVIEW_____

_____

_____

Preamble:

I want to find out about your own experience with hypothyroidism. Tell me in your own words and with as much detail as possible. There is no need to rush. If you have any questions during the interview, please feel free to ask them. Let's start at the beginning:

1. **TELL ME ABOUT YOUR EXPERIENCES LEADING UP TO THE DISCOVERY THAT YOU HAD HYPOTHYROIDISM.**
   PROBES: What signs and symptoms did you have?
   When did you first notice them?
   Did others notice them?
   What did you think was wrong with you?
   How did this affect you, your family, your work?
   Tell me about when you first saw a doctor and what convinced you to go?
   Was hypothyroidism his first diagnosis?
   If yes: What treatment was started?
   If no: What other diagnosis(es)?
   What diagnostic tests were done?
   Did you ever suspect that you had hypothyroidism before it was diagnosed by your doctor?
   Did you ever seek help from any other type of medical practitioner?
   When you were told that you had hypothyroidism, how did you feel?
   How did you learn more about the disease?

2. **WHAT TREATMENT HAVE YOU HAD FOR YOUR HYPOTHYROIDISM?**
   PROBES: Medication?
   Any other?
   How did it make you feel? --at first?
   --over time?
   Have you ever stopped, or been tempted to stop taking your medication?

3. **OVERALL, HOW HAS HAVING HYPOTHYROIDISM AFFECTED YOUR LIFE?**
   PROBES: Any difficulties with family, friends? work?
   before diagnosis?
   since diagnosis?
   Have you been able to overcome these difficulties?
   What is the worst thing that has happened as a result of having hypothyroidism?
   Any good things?

4. **HOW DO YOU FEEL NOW?**
   PROBES: Do you feel completely recovered?
   Are you satisfied with your life?
   Are you satisfied with your doctor?
   How is your life (family, friends, work) different now.

5. **IS THERE ANYTHING ELSE YOU WOULD LIKE TO TELL ME ABOUT WHAT IT IS LIKE TO HAVE HYPOTHYROIDISM?**

APPENDIX F INTERVIEW CONSENT FORM

The purpose of this research is to learn about the illness experience of women with hypothyroidism. In consenting to help with this study, I understand and agree with the following statements:

1. I give permission to be interviewed and for this interview to be tape-recorded. I understand that, at the completion of the research project, the tapes will be erased.

2. I understand that I am free to refuse to answer any specific question(s) and that I may withdraw my consent and end the interview at any time, without penalty.

3. I have been given the opportunity to ask any questions I wish about the study, and these questions have been answered to my satisfaction.

4. I give permission to Mrs. Jane Milliken to quote from and refer to the content of this interview in academic talks and professional writing, subject to any requests or limitations that I may make on the tape itself, concerning specific topics or statements.

5. I also understand that Mrs. Jane Milliken will ensure my privacy and anonymity when citing any material from this interview.

6. The interview is expected to last approximately one hour. In the event that a follow-up interview is requested, it will be my choice whether or not to participate.

Interviewee_____

Dated and signed on_____

Interviewer_____

Dated and signed on_____